

Report of the Data Working Group Meeting Intercultural Cancer Council

September 25-26, 1999
Washington, DC

Introduction

A meeting of the Data Working Group of the Intercultural Cancer Council (ICC) was held on September 25-26, 1999, in Washington, DC. (A list of participants for the September meeting is provided in Appendix A.) This was the first of two meetings on work in progress to address improving databases concerning cancer in ethnic minorities and the medically underserved. The purpose of this first meeting was to identify the specific cancer data gaps for ethnic minorities and the medically underserved, as represented by the members of the ICC and noted in the Institute of Medicine (IOM) report entitled *The Unequal Burden of Cancer* (1999). (The agenda for the September meeting is presented in Appendix B.) Database issues were identified by examining what data are being collected on these populations, how these data are being collected, and who is collecting the data. Presentations were made to inform Working Group members about the steps being taken by the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), the American Cancer Society (ACS), the National Center for Health Statistics (NCHS), and others to fill these gaps. The report from this first meeting will be used by representatives of NAACCR, NCI, NCHS, CDC, ACS, and the ICC at a meeting on November 14-15, 1999, in Houston, TX, to examine the future specific approaches, methodologies, and activities by all needed to improve national and local/regional cancer data.

ICC Working Group members attending the September meeting were asked to prepare responses to the following five questions regarding data needs for ethnic minorities and the medically underserved:

1. List the cancer incidence and survival data needs for your “special population,” which should and could be collected by a central registry. Why are these data needed? How much detail is required? Is socioeconomic status (SES) important in analyzing data from your group(s)? What elements of SES would be appropriate for your group(s)? What cultural characteristics must be considered in collecting or analyzing data from your group(s)?
2. What information is being collection? By whom? Are the data needs—for cancer control purposes—being met with regard to quality as well as completeness?
3. What data are not being collected? Where are the gaps? What are the obstacles to collecting such data? Are there accurate numerators and denominators?
4. Is there a particular subgroup from which these data are, or could be, collected that would be representative of the larger group? In your population, how many subgroups are there from which data could or should be collected? What is the size of these groups and their geographic locations?
5. What proportion of your population is “medically underserved”? How is this defined for this group?

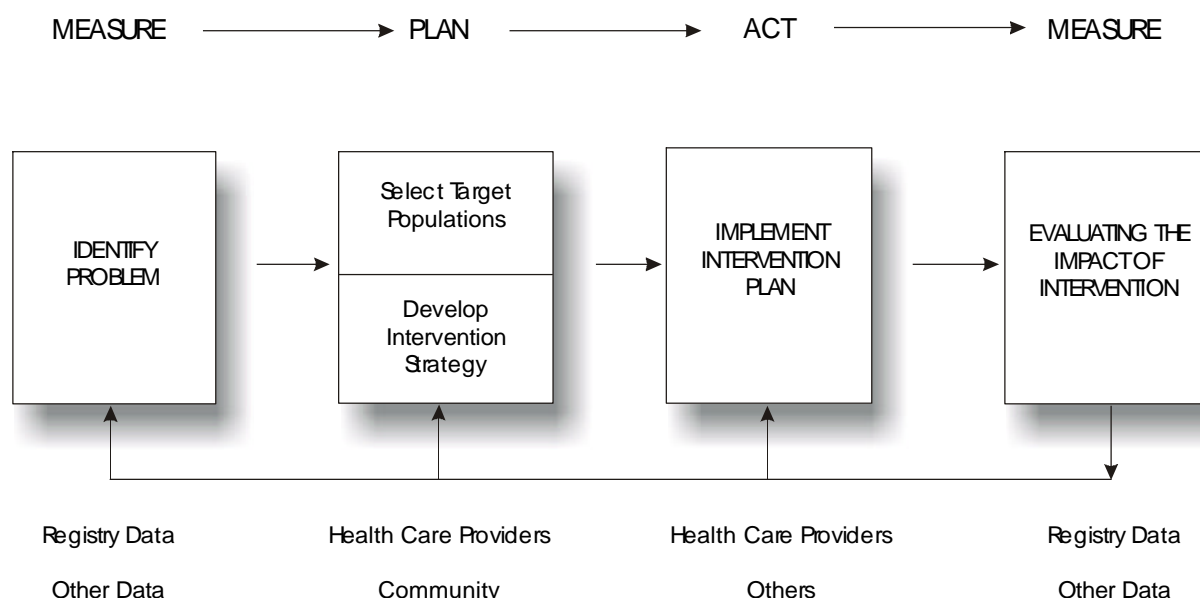
Presentations

Statement of the Problem—Dr. Gilbert Friedell

Dr. Gilbert Friedell provided an overview of the data gaps described in the IOM report. The IOM's Committee on Cancer Research Among Minorities and the Medically Underserved found that NCI's Surveillance, Epidemiology, and End Results (SEER) program provides high-quality data that is the best approximation of a national cancer database; however, **the SEER program, does not fully describe the burden of cancer for many U.S. ethnic minority and medically underserved populations. It lacks the necessary database concerning the disproportionate cancer incidence, mortality, and survival rates among ethnic minorities and the medically underserved that would permit the development and evaluation of effective cancer control strategies for these populations.** The Committee recommended that the SEER program's efforts be enhanced by:

- h Developing uniform definitions of “special populations with cancer” and “medically underserved” as well as collection and reporting of data for medically underserved populations.
- h Expanding SEER program coverage to include high-risk populations for which SEER program coverage is lacking. This expansion should address a wider range of demographic and social characteristics by using consistent nomenclature and a uniform data set and by reflecting the diverse characteristics of the U.S. population.
- h Continuing to work with NAACCR and other organizations to expand the coverage and enhance the quality of the 45 non-SEER program state cancer registries to achieve: (1) a truly national data set obtained through a system of longitudinal population-based cancer registries covering the entire country, and (2) a reliable database for each state to serve as the basis for both the development and evaluation of cancer control efforts in that state.
- h Expanding annual reporting of cancer surveillance data to include survival data for all ethnic groups as well as for medically underserved populations.
- h Conducting behavioral and epidemiologic research examining the relationship between cancer and cancer risk factors associated both across and within various ethnic minority and medically underserved groups.

The application of cancer control interventions varies from one community to another, and in some populations there has been relatively little improvement in cancer morbidity and mortality during the past several years. The approach to cancer control for these populations must be changed so that meaningful community involvement is achieved. This process begins with re-evaluating the type and amount of information being collected and disseminated. This information must be understandable, meaningful, and relevant. In Kentucky, it has become apparent that successful cancer control program development goes through four stages. This four-step cancer control model involves: (1) using data from a population-based cancer registry and other sources to identify the problem; (2) ensuring community involvement with providers in selecting the target population and developing the intervention strategy; (3) implementing the intervention plan; and (4) using cancer registry and other data to evaluate the impact of the intervention. This cancer control model is depicted in Figure 1.

Figure 1. Cancer Control Model

As recommended in the IOM Report, the NIH should develop a uniform definition of “special populations,” which currently include American Indians/Alaska Natives, Asians, Pacific Islanders, Hispanics, African Americans, the Elderly, and Low Income who are often Low Literate, Rural, and employed in High Risk Occupations.

[At the September 1999 National Cancer Advisory Board meeting, Dr. Frederick Li reported that the NCI has defined “special populations” as ethnic minorities, rural, low income, and low literacy groups. This report also indicated that the medically underserved should not be grouped with special populations, because of the complexity of defining the term “medically underserved.”] A common definition of the medically underserved (e.g., under-insured or uninsured, low education levels, rural and inner city, unemployed, and low SES) should be developed for use throughout the federal government. [The NCI sponsored a meeting held on July 23, 1999, to define the medically underserved. Subsequent meetings are planned to continue discussions to define and characterize the medically underserved. The findings from this conference will be presented at the November meeting in Houston, TX.]

The incidence of lung and bronchus cancer is higher in whites in Eastern Kentucky (KY Cancer Registry, 1992) than in other non-Hispanic whites (SEER, 1988-1992) in the United States. This difference probably is attributable to SES and smoking prevalence. Examination of the combined rates of Cancer in North America (1991-1995) compiled by the Data Evaluation and Publication Committee of NAACCR, indicates that breast cancer is the most commonly diagnosed cancer among females of all ethnic groups in the United States (see Table 1). For men, prostate cancer is the most commonly diagnosed cancer among white, African American, Filipino, Japanese, Chinese, and American Indian/Eskimo/Aleut men as well as men of other races (see Table 2). Lung cancer is the most commonly diagnosed cancer among Vietnamese and Korean men, with prostate cancer ranked third and fifth, respectively, in these two ethnic groups. The IOM Report stressed the importance of studying populations with lower incidences, and the Cancer in North America (CINA) data is useful in identifying those populations; data published in CINA

Table 1. Top Five Most Commonly Diagnosed Cancers* in Females in the United States by Ethnic Group, 1991-1995

All Races (total new cases = 1,237,785)		White (total new cases = 1,096,924)	
Breast	30%	Breast	31%
Lung	13%	Lung	13%
Colon & Rectum	13%	Colon & Rectum	13%
Corpus & Uterus	6%	Corpus & Uterus	6%
Ovary	4%	Ovary	4%
African American (total new cases = 91,397)		Filipino (total new cases = 6,946)	
Breast	29%	Breast	33%
Colon & Rectum	13%	Colon & Rectum	9%
Lung	13%	Lung	7%
Cervix	5%	Thyroid	7%
Corpus & Uterus	5%	Corpus & Uterus	6%
Japanese (total new cases = 6,812)		Chinese (total new cases = 5,986)	
Breast	32%	Breast	27%
Colon & Rectum	17%	Colon & Rectum	11%
Lung	8%	Lung	9%
Stomach	7%	Corpus & Uterus	4%
Corpus & Uterus	6%	Ovary	4%
Korean (total new cases = 2,097)		Vietnamese (total new cases = 2,048)	
Breast	20%	Breast	21%
Colon & Rectum	11%	Cervix	11%
Stomach	11%	Colon & Rectum	9%
Cervix	8%	Lung	9%
Lung	8%	Thyroid	7%
Am Indian, Eskimo, Aleut (total new cases = 1,750)		Other Races (total new cases = 23,825)	
Breast	24%	Breast	29%
Lung	12%	Melanomas of Skin	10%
Colon & Rectum	11%	Colon & Rectum	8%
Ovary	6%	Corpus & Uterus	6%
Corpus & Uterus	5%	Lung	6%

* Compiled by the Data Evaluation & Publication Committee of the North American Association of Central Cancer Registries, based on cases included in the combined rates of Cancer in North America, 1991-1995.

meets established levels of quality, although not as rigorous as those maintained in the SEER Program. The purpose of this meeting is to determine what data elements should be collected on ethnic minority and medically underserved populations. Much of the information presented by Dr. Friedell is included in the article entitled "What Providers Should Know About Community Cancer Control" (*Cancer Practice* 1997; 5(6):367-374).

**Table 2. Top Five Most Commonly Diagnosed Cancers* in Males
in the United States by Ethnic Group, 1991-1995**

All Races (total new cases = 1,393,133)		White (total new cases = 1,220,466)	
Prostate	31%	Prostate	31%
Lung	16%	Lung	16%
Colon & Rectum	10%	Colon & Rectum	12%
Bladder	6%	Bladder	7%
Non-Hodgkin's Lymphoma	4%	Non-Hodgkin's Lymphoma	4%
African American (total new cases = 112,233)		Filipino (total new cases = 7,598)	
Prostate	34%	Prostate	31%
Lung	20%	Lung	18%
Colon & Rectum	10%	Colon & Rectum	12%
Non-Hodgkin's Lymphoma	3%	Non-Hodgkin's Lymphoma	5%
Stomach	3%	Liver	3%
Japanese (total new cases = 7,373)		Chinese (total new cases = 6,779)	
Prostate	32%	Prostate	20%
Colon & Rectum	18%	Lung	17%
Lung	12%	Colon & Rectum	16%
Stomach	8%	Liver	7%
Bladder	5%	Stomach	5%
Vietnamese (total new cases = 1,989)		Korean (total new cases = 1,920)	
Lung	18%	Lung	17%
Liver	13%	Stomach	16%
Prostate	11%	Colon & Rectum	12%
Colon & Rectum	10%	Liver	10%
Stomach	7%	Prostate	9%
Am Indian, Eskimo, Aleut (total new cases = 1,746)		Other Races (total new cases = 33,029)	
Prostate	20%	Prostate	46%
Lung	16%	Melanomas of Skin	8%
Colon & Rectum	12%	Lung	7%
Kidney & Renal Pelvis	6%	Colon & Rectum	7%
Non-Hodgkin's Lymphoma	4%	Bladder	4%

* Compiled by the Data Evaluation & Publication Committee of the North American Association of Central Cancer Registries, based on cases included in the combined rates of Cancer in North America, 1991-1995.

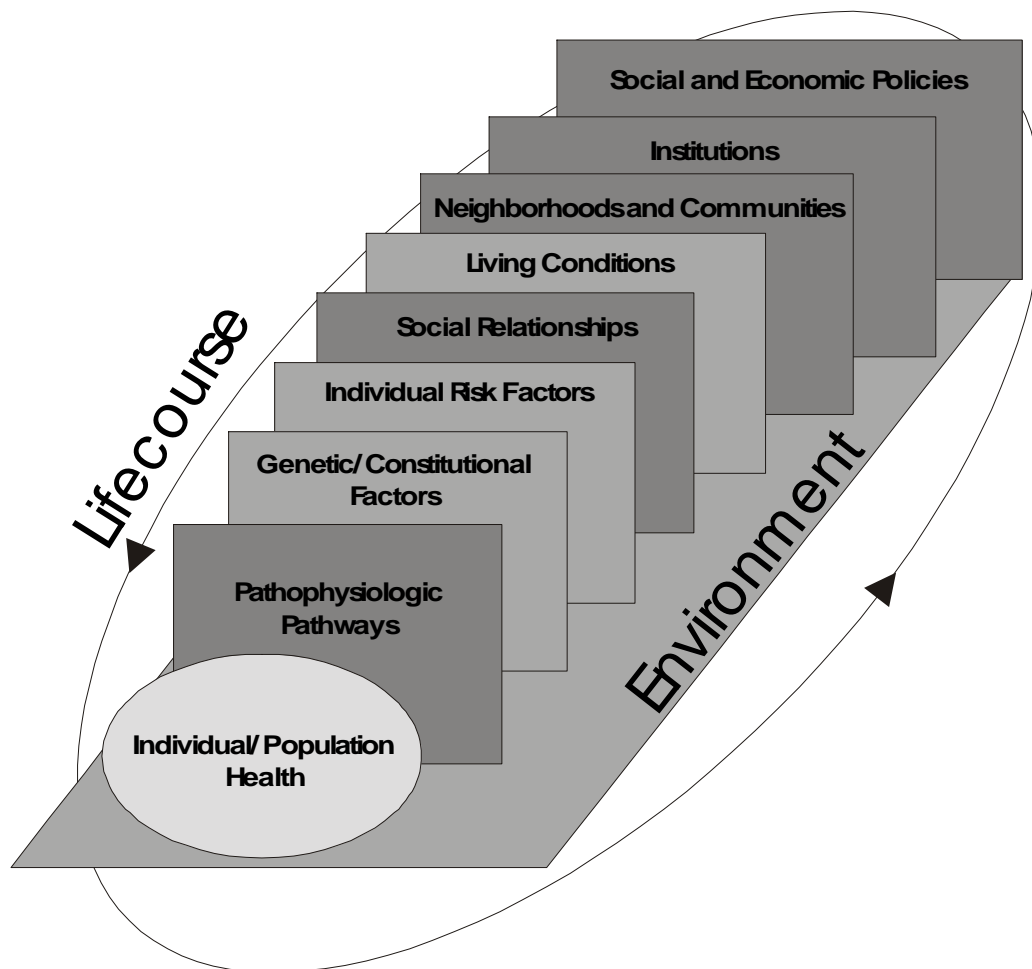
The NCI Cancer Control Research Perspective—Dr. Robert Hiatt

Dr. Robert Hiatt indicated that NCI's overall goal is to reduce the cancer burden of the U.S. population. To accomplish this goal, it is important to explain the disparities in cancer incidence and survival rates among different populations. Since the 1990s, there has been a decline in the cancer mortality rates for several types of cancer. However, this is not true for all population groups. We need to understand and be able to explain the differences in cancer rates among populations groups. As illustrated in Figure 2,

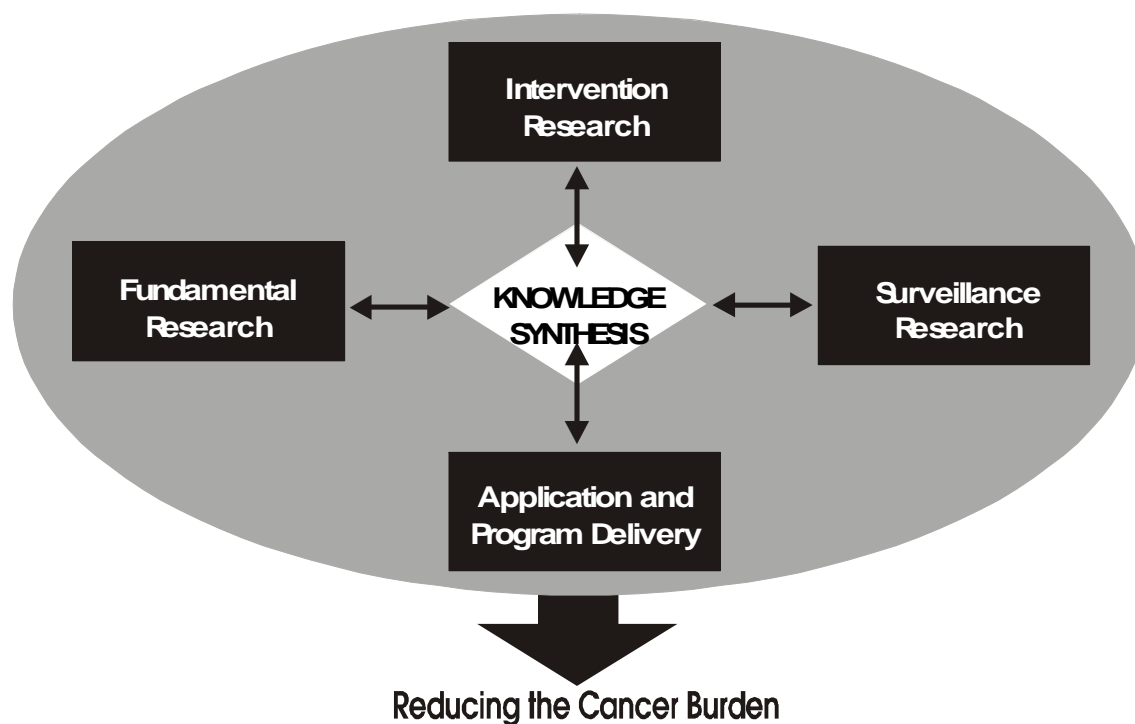
there are a number of factors that impact health during the lifecourse (i.e., pathophysiologic pathways, genetic/constitutional factors, individual risk factors, social relationships, living conditions, neighborhoods and communities, institutions, and social and economic policies). The NCI needs to shift some research dollars toward the broader sociocultural “upstream” factors.

As depicted in Figure 3, cancer control research activities are interrelated. What we learn in fundamental research informs intervention research; intervention research tells us what works; and surveillance research tells us where we are with respect to the cancer burden. Before fundamental research can

Figure 2. Upstream Factors That Impact Health During the Lifecourse



contribute to intervention research, the data must be analyzed and knowledge must be synthesized. Once we know what is effective, it should be translated into applications. The federal government is spending substantial amounts of money to ensure that we apply what has been learned. Several groups within NCI's Division of Cancer Control and Population Sciences (DCCPS) are supporting relevant research, including the Cancer Statistics Branch (responsible for administering the SEER program), the Epidemiology and Genetics Research Program (etiologic research), and the Applied Research Program (develops methods to assist surveillance efforts and to link SEER data with other data sets such as Medicare). The NCI is trying to build a better program that will facilitate understanding of the population-level, sociocultural influences on cancer outcomes. Each of these programs has **a broad plan**

Figure 3. Cancer Control Research Activities

for applied research that has SEER at its core. The data collected by SEER are critical to understanding the cancer burden. Much of the information needed to explain the trends that emerge from SEER results from applied research conducted by NCI's Applied Research Program and the extramural research community. These efforts have expanded our capacity to explain the underlying reasons for trends in the cancer burden and variations among ethnic populations and subgroups.

The ideal cancer surveillance system for the U.S. population would be a functional registry in every state and territory. Such a system would allow us to pool surveillance data to identify differences among population groups. It also would enable us to detect geographical differences. Therefore, one of NCI's goals is to assist in achieving complete coverage for all states. This can be accomplished through collaboration with CDC's National Program of Cancer Registries (NPCR) and the NAACCR through the NCCCS. The NPCR registries collect incidence and demographic data. The SEER registries collect this information as well as additional data to help explain why there are differences among population groups over time. Because the SEER program does not fully represent a number of ethnic minority and medically underserved populations, the NCI is in the process of developing a Request for Proposals to add three or four states/regions to the SEER program. This expansion, which will be conducted in coordination with the CDC, will provide a richer database to answer critical questions concerning the disparities in cancer rates among different population groups. Presently, there is variable quality among the state registries and it will take some time before all states can submit data that meet the required standards for publication in a pooled data report. However, even without high-quality data from every state, SEER and the NPCR can provide valuable information needed to facilitate a reduction in the cancer burden. These are some of the steps that the NCI is taking to address the concerns expressed in the IOM Report.

Dr. Ho indicated that two common concerns are confidentiality and access to information. Although we need to collect these data, we have to protect the right to privacy of the individuals. If an informed

consent must be obtained from each individual included in a registry, many individuals will refuse to sign the consent form. [The NCI has planned a meeting, which will be held on December 1-2, 1999, to develop best practices ensuring confidentiality in the conduct of clinical research. The meeting participants will focus on particular research areas, including clinical trials, databases and surveillance, epidemiology, human genetics, and archived human specimens. Participants will include investigators, patient advocates, informatics experts, members of professional societies, agency representatives, ethicists, and Congressional staffers. The results of this meeting will allow Dr. Klausner (NCI Director) to provide input to the Secretary of Health and Human Services, who will be promulgating guidelines about medical confidentiality by February 1, 2000. These guidelines are available on the Web at <http://aspe.hhs.gov/admnsimp>.]

Dr. Hiatt agreed that these are important concerns and he urged everyone to stress the importance of cancer registration to their representatives. Dr. Friedell thanked Dr. Hiatt for his presentation and noted that federal involvement in cancer registration is necessary to address the variations among the states.

When asked if it is likely that the states/regions meeting the criteria for the new SEER sites will fill the population gaps associated with SEER, Dr. Hiatt responded that, although they will fill some of those gaps, he could not predict whether the sites selected will satisfy all parties concerned about gaps in population coverage by SEER. He also noted that the NCI has allocated funds within its budget to assist non-SEER registries in improving the quality of their surveillance data. The NCI will explore mechanisms such as Interagency Agreements with the CDC to work with NPCR registries to help them improve data quality. Dr. Hiatt pointed out that well-trained, dedicated individuals are critical to a high-quality registry. The SEER program has been so successful because it has knowledgeable investigators at SEER sites who are committed to surveillance research; these individuals have an interest in surveillance science and they publish in the field.

Issues for American Indian and Alaska Native Populations—Drs. James Hampton, Jeff Henderson, and Laura Williams

Dr. James Hampton read an excerpt from the IOM Report (page 61), which described four facts that are found consistently in studies examining cancer incidence among American Indian populations:

- h Cancer is the second leading cause of death among American Indians.
- h American Indians have the lowest 5-year survival rate for all cancers when compared to other populations.
- h American Indians have the highest percentage of disseminated and ill-defined cancers.
- h Very little is known about prevention and treatment patterns for cancer in American Indians.

The SEER program collects information on cancer incidence, mortality, and survival for American Indians at each SEER site (including those living in New Mexico and Arizona—the southwestern American Indians), and Alaska Natives in Alaska. CINA data indicate that there is significant incidence of renal cancer among Native Americans in Alaska and other areas of the United States and Canada. Such unusual cancers need to be explained, but before that can be accomplished we need reliable data. Generalizing the incidence from SEER data leads to inaccurate estimates of the cancer burden among Native Americans.

Dr. Jeff Henderson, who is the Principal Investigator for a nationwide clinical intervention for heart and diabetes prevention, indicated that there is increasing concern about cancer among Native Americans.

Efforts are ongoing to improve collection of cancer data for American Indians in the Northern Plains states. The Rapid City Regional Hospital in Rapid City, SD, established a cancer registry in 1993. Cancer statistics also are collected by the South Dakota Cancer Data Collection Program—a consortium of medical centers in Aberdeen, Sioux Falls, and Rapid City. Although these are helpful, many American Indians referred to these three medical centers are misclassified and many Native American cancer patients are not seen at these hospitals because they are referred to facilities outside of the area (e.g., Mayo Clinic). The SEER program currently does not operate a cancer registry in the northern plains. Significant improvements could be made in the current efforts to capture cancer information on northern plains American Indians. For example, we could make better use of the data collected by the Indian Health Service (IHS). The National Indian Council on Aging, Inc., in Albuquerque, NM, was awarded a grant from the IHS to receive their data from the Parklawn Computer Center (PCC) in Rockville, MD. The National Indian Council on Aging recently published a monograph that reported the leading causes of death among American Indian elders using the 10 data sets obtained from the PCC. The monograph reports cancer death rates by county, indicating that the highest cancer death rates occur in the north central region of the IHS service area. The Bemidji area has the highest cancer death rate and the California area has the lowest rate. There also are very high cancer death rates in some southwest counties and high rates in some northwest and east coast counties. The IHS data provided to the National Indian Council on Aging could be the most accurate and meaningful collection of cancer death rate data on American Indians available today and it could be very valuable to organizations involved in cancer surveillance.

When asked about how much of the American Indian population lives outside of reservations, Dr. Henderson responded that there are 558 federally recognized tribes who speak 320 different dialects of language with 12 different families of language. Approximately 40 percent of American Indians live on tribal reservation land; the other 60 percent live in urban and rural areas. He had no data regarding how many American Indians living off reservation are being counted in the Census. Dr. Williams added that there are a number of tribes that are recognized by the state but not the federal government. She indicated that no data are collected **by IHS** on those tribes. Dr. Williams also **(need reference)** noted that there is a 40-50 percent misclassification of American Indians as either white or Hispanic.

Issues for Hispanic Populations—Drs. Amelie Ramirez and Jeannette Noltinius

Dr. Jeannette Noltinius indicated that the Latino Council on Alcohol and Tobacco is very concerned about cancer because approximately 34 and 32.9 percent of young Latino males and females, respectively, are smoking.

With regard to data needs, more extensive coverage is needed on all the Latino population groups (e.g., Central American, Mexican, Puerto Rican, and Cuban). SES information (at a minimum income and education) should be collected for all the population groups. Information on cultural characteristics (e.g., acculturation measures, language use, country of birth) should be collected. Occupational data (e.g., usual/lifetime occupation and/or industry) would be useful because it may provide insight into risk factors. In addition, states that have high prevalence of poverty must be included and surveillance must be broadened to include all Hispanic groups. This is particularly important because Hispanics are moving to areas where they have not traditionally located (e.g., Kentucky, Georgia, and North Carolina).

Hispanic origin data routinely are collected by all cancer registries that are members of NAACCR. The SEER program collects Hispanic origin data, but it has published limited data for Hispanic **subgroups (see NAACCR report)**. Hospital personnel collect data on incidence from medical records; mortality data are from death certificates. Ethnicity identification typically is based on subjective appraisals by hospital personnel; therefore, the quality of the classification data is limited by the quality of the information provided in hospital records. Death data are poor because of misclassifications by **the**

individuals completing the death certificates (often this individual is not familiar with the deceased). The SEER program currently is the only cancer registry system with the resources to collect sufficient followup data to allow for accurate, timely survival statistics. Additional financial resources are needed to support this activity through the SEER program and to collect information on all Hispanic groups. In addition, more information is needed on the number of individuals who are receiving medical care outside of the United States and why they are seeking care in another country. We also need to learn more about quality of life issues for all Hispanic groups (see SEER Special Studies).

In regard to quality and completeness of data for cancer control purposes, the coverage **in some states** is incomplete and misclassification of Hispanic ethnicity is a problem. Furthermore, there has been no clear-cut procedure developed at the medical record level to standardize the assignment of Hispanic origin. Is a Hispanic someone who is genetically Hispanic or someone who is culturally Hispanic? Because ethnicity data are being determined by different methods, it is difficult to interpret and compare differences in rates. Questionable accuracy of these classification methods combined with discrepancies between them, creates doubt about the overall accuracy of Hispanic cancer rate determinations and casts further suspicion on comparisons between ethnic groups. Based on classification discrepancies, cancer risk among Hispanics may either be underestimated or overestimated. Ethnic classifications based on medical records alone have been found to underestimate cancer incidence rates, which may at least partially account for the lower rates found in studies of registry-based cancer incidence in Hispanics. Denominators also are a problem because of ethnic classification errors.

There is no “typical” Hispanic. This is a highly diversified population, and its heterogeneity makes it difficult to apply broad generalizations to the Hispanic population as a whole. Although Hispanics of various ethnic origins can be found throughout the United States, concentrations of the population are particularly large in 10 states (i.e., California, New Mexico, Arizona, Texas, Colorado, New York, New Jersey, Massachusetts, Illinois, and Florida) and Puerto Rico. In broad terms, there are subgroup/region correlations, such as Mexican Americans in Texas, Cuban Americans in Florida, and Puerto Ricans in New York. Of the 31 million Hispanics in the United States, approximately 64 percent are Mexican Americans, 14 percent are Central and South Americans, 11 percent are Puerto Ricans, 4 percent are Cuban Americans, and the remainder are of “other” origin. The major subgroups of Hispanics should be covered by cancer registries. At a minimum, Mexican Americans (12 million residing in Texas, California, Illinois, Colorado, New Mexico, and Arizona), Cuban Americans (1 million residing primarily in Florida), Puerto Ricans (3 million residing in New York, New Jersey, Pennsylvania, Connecticut, and Florida), Central Americans (1.5 million residing in California and the eastern seaboard) should be included in cancer registries. These subgroups are probably distinct in terms of exposure and possibly etiology as well; therefore, it does not seem feasible to target any particular subgroup in the hope of generalizing their data to all Hispanics.

The poverty rate for Hispanics is 28 percent, but this rate varies tremendously by Hispanic population groups. One-third of Hispanics are uninsured; 60 percent of Hispanics in the Washington, DC, area are uninsured.

Dr. Amelie Ramirez pointed out that there are a number of organizations that need to be included in any effort to collect cancer data on Hispanics. These include the National Hispanic Medical Association and the Hispanic-Serving Health Professions Schools (18 member schools). To become a member of the latter organization, at least 9 percent of the school’s student enrollment must be Hispanic; schools with 5-8 percent Hispanic student enrollment are eligible for associate membership. This organization is developing a fellowship program to fund Hispanic research. Dr. Ramirez stressed the need to be sensitive in collecting data from the Hispanic community as well as the importance of cultural competence in obtaining good data.

Mr. Barry Miller commented on Dr. Noltenius' statement about the SEER program not publishing data for Hispanics. He indicated that data have not been published on Hispanic subgroups because of the lack of denominators for population subgroups that are needed to calculate cancer rates. The NCI has been working with the Census Bureau to obtain denominators for these Hispanic subgroups and there are plans to publish incidence and mortality rates for Hispanic subgroups in SEER. **[During the next 10 years, the Long-Form Census probably will be replaced by the American Community Survey, which will change the way denominators are obtained for intercensal years and for details on population characteristics. Unlike the Census that is collected every 10 years, the American Community Survey will be a rolling survey to provide better, more current data. Dr. Elena Rios noted that the community as well as health providers need to be involved in data collection and educated about its importance to the health care delivery of the community.]**

Issues for African American Populations—Drs. Sandral Hullett and Lovell Jones

Dr. Sandral Hullett provided an overview of the issues for African American populations. There is a substantial amount of cancer data on African Americans and it is evident that cancer rates are high among the African American population. The IOM Report indicated that 30.7 percent of African Americans are below the poverty level. Of the 9.5 million African Americans that lived below the poverty level in 1987, 7.3 million resided in metropolitan areas and 2.2 million lived in non-metropolitan areas. Dr. Hullett stressed the importance of collecting information on family structure and roles, health beliefs, religious beliefs, sexual attitudes/practices, drug use, and other factors. To make an impact, emphasis must be placed on community-based research that promotes the involvement of the community in the data collection process.

Dr. Lovell Jones noted that there are very few African American epidemiologists collecting cancer data. This is a concern among the African American community. Dr. Jones presented the following quote by Dr. Martin Luther King, Jr.:

“If you want to move people, it has to be toward a vision that is positive for them, that taps important values, that gets them something that they desire, and it has to be presented in a compelling way that they feel inspired to follow.”

Although race has no biological basis, it leads to racism and racialism. These have an impact on data collection. It is important to take culture into account when assessing health risk. Although SEER data indicate that there has been a decline in the cancer mortality rates for several types of cancer, this is not evident among African Americans. Dr. Jones stressed the fact that SEER should be a research tool not a survey. There is a need to look at other databases and innovative approaches—we cannot just add more SEER registries to address this problem. “If you always do what you always did, you will always get what you have already got.” Immigrant populations are changing the entire dynamics of the African American population. What impact does this have on the native population?

Issues for Asian American and Pacific Islander Populations—Susan Shinagawa, Evaon Wong-Kim, and Dr. Reggie Ho

Ms. Susan Shinagawa described data collection issues for Asian Americans. The total U.S. Asian population in 1990 was approximately 7,172,500 (about 3 percent of the total U.S. population). The year 2000 projection for the Asian population is 10,682,750 (approximately 4 percent of the total U.S. population). In 1998, more than 70 percent of the total Asian population in the United States resided in seven states—California, New York, Hawaii, Texas, New Jersey, Illinois, and Washington. The top 10 counties/metropolitan areas nationwide with the largest Asian and Pacific Islander populations (aggregate) are Los Angeles, New York, Santa Clara, Orange, San Francisco, San Diego, Chicago,

Alameda, Washington, DC, and Houston. SEER collects incidence and survival data for Asians and Pacific Islanders (APIs), but the data are aggregated. CDC's NPCR collects incidence data in 45 states, 3 territories, and the District of Columbia; however, the level and quality of surveillance varies among the different states. The Northern California Cancer Center in the San Francisco Bay Area has analyzed data on cancer rates in some Asian countries as well as data on immigrants from China, Japan, and the Philippines. Ms. Shinagawa stressed the importance of disaggregating Asian Americans from Pacific Islanders. These are very different populations with very different problems. There is a need to look at subpopulations (at least 30 different groups).

Approximately 60 percent of the U.S. API population resided in the states of California and Hawaii at the time of the 1990 Census. As a result, API populations, as an aggregate group, are well represented in the SEER program, which has registries in the metropolitan areas of San Francisco/Oakland, San Jose/Monterey, and Los Angeles in California; the state of Hawaii; and the metropolitan area of Seattle, Washington. However, disaggregated rates are needed—separating “Native Hawaiians and Other Pacific Islanders” from “Asians” and disaggregating the “Pacific Islander” as well as the “Asian” subpopulation groups. In addition, more refined category distinctions in Asian American and Pacific Islander groups in the SEER program is needed to include more of these disaggregated subpopulation groups.

Several behavioral and cultural risk factors in the Asian American and Pacific Islander groups impact cancer rates (e.g., smoking prevalence, Hepatitis B, exercise, diet, and nutrition). Behavioral surveillance surveys typically are conducted by telephone in English. More than two-thirds of California's API population are first-generation immigrants who speak limited English and approximately 35 percent of the API elderly are non-English speaking. Therefore, only a limited percentage of the behavioral risk factor data collected by California actually reflects these factors for the state's API population. For many states, the few data that are collected are reported for APIs as an aggregate group, limiting their use. Information on behavioral risk factors (e.g., nutrition, diet, exercise, and smoking) and screening behaviors (e.g., what proportion has been immunized against Hepatitis B virus, who is being screened for what cancer and by what risk factor) is very limited. The CDC should be more specific in collecting Asian subpopulation and ethnicity data when they do their breast and cervical screenings.

The main deficiency in reporting APIs as an aggregate group for cancer surveillance is that statistically significant outliers in specific subpopulations (e.g., Hmong, Cambodian, and Lao), are obscured. For behavioral risk factor data, the deficiencies in reporting APIs as an aggregate group are that statistically significant outliers in specific subpopulation groups may be obscured, or more likely, not collected at all. Most surveys that collect information on behavioral and cultural characteristics are conducted in English and a large proportion of Asian Americans are immigrants with limited or no English-speaking abilities. The Behavioral Risk Factor Surveillance Survey (BRFSS), for example, is collected by states only from English-speaking individuals. Approximately 34.9 percent of all U.S. Asian households are linguistically isolated (i.e., there is no one over the age of 13 in the household that speaks English). Asian Americans speak more than 100 languages and different dialects. Because the API population has grown substantially, primarily due to new and older immigrants, the number of linguistically isolated households has risen. In addition, many non-English speaking immigrants are not willing to participate in any type of research. They are extremely suspicious about surveys and the Western medicine tradition. It is important to collect data on the level of acculturation or assimilation into American society. Among Asian Americans, social characteristics and income vary greatly. Overall, English-speaking APIs have higher SES, educational attainment, and better health. California is not collecting behavioral risk factor data for the more than two-thirds of Asian Americans who do not speak English or have limited English. In 2000, the California Health Interview Survey (CHIS) was fielded for the first time. This is a telephone survey that is designed to provide population-based, standardized health-related data from 55,000 households selected from all 58 counties in California. Sampling will be conducted to provide county-level data to characterize health needs for at least three ethnic groups in each of the 34 counties with a

population of more than 100,000. For the eight counties with populations of 50,000-100,000, at least two ethnic groups will be reported, and for smaller counties, county-level or aggregate-county level data will be provided. The minimum sample for each ethnic group will be 300. Data items collected may include a roster of household and family members, social and demographic information, health insurance information, activity levels, quality of life, health conditions (including height and weight, injuries, heart and lung disease, cancer, allergies), health behaviors (smoking, physical activity, alcohol consumption, diet), and health services utilization. The content related to cancer prevention and control includes screening for breast, colorectal, cervical, and prostate cancers and sun avoidance as well as the health behaviors listed above. Data are collected on a number of factors, such as health insurance, that may influence cancer prevention and control behaviors.

There also is a need to disaggregate immigrants from those who have been in the United States for generations. For some cancers, Asian Americans lose their protective cultural factors (e.g., breast) after immigrating to the United States; for other cancers, they gain protective factors (e.g., nasal, pharyngeal). Disaggregation is necessary to examine why these changes in protective factors occur. For Asian American women, cancer has been the leading cause of death; for Asian American men the leading cause of death is heart disease, but cancer is close behind. There is minimal information available on Asian immigrant subpopulations.

There is no accurate numerator or denominator for many groups of Asian Americans. Therefore, we are unable to calculate cancer rates for these groups. Currently, deficient data for Asian Americans include:

- h Accurate Census denominators
- h Detailed subpopulation data (ethnicity)
- h Consistent, disaggregation of data by subpopulation (ethnicity)
- h Accurate mortality rates (due to misclassification and the numbers of uncounted deaths due to Asians who “go home to die”)
- h Sufficient and accurate behavioral risk factor data
- h SES
- h Immigrant versus non-immigrant status
- h Country of nativity
- h Generation in the United States
- h Residency (urban versus rural; environmental injustice or other environmental factors).

Data on behavioral risk factors by ethnicity for Asian subpopulations are needed, along with length of survival and quality of life during the survival interval. **The next Cancer Control Supplement of the National Health Interview Survey (NHIS) will include a section on acculturation and California will field the CHIS to obtain data on culture characteristics for Asian and Pacific Islander populations (see <http://appliedresearch.cancer.gov/RiskFactor/chis.html>).** SES factors also are important because many recently immigrated Asians have problems accessing health care and cancer screening services. This also is true for many Pacific Islanders. Specific elements appropriate for Asian subpopulations include English proficiency; personal, not family income; educational attainment; employment; health care coverage (whether one has coverage and what type of coverage one has); number of members in household supported by the income; and number of years living in the United States. The specific elements appropriate for Pacific Islander subpopulations include English proficiency, total family wealth/discretionary income, and insurance status.

In 1990, 14.1 percent of all APIs (aggregate) lived in poverty (e.g., Hmong 63.6 percent, Cambodian 42.6 percent, and Lao 34.7 percent as compared with the total U.S. poverty rate of 20 percent) and had limited

or no access to medical services due to lack of insurance (in California, 24 percent of APIs [aggregate] are uninsured). Newer immigrant Asian populations have a markedly higher rate of uninsured individuals (the “working poor”). Among U.S. Asians, there are numerous barriers to accessing health care services that are associated with low SES (e.g., transportation, childcare, and inflexible work hours with lack of sick leave). Approximately 50 percent of the Asian American population may be medically underserved.

Too often our efforts are focused on populations that have higher cancer rates than the white population. There is a need to look at the protective factors that are lost in the acculturation process. For example, soy products may be responsible for the reduced breast cancer incidence among Asians; green tea (as an antioxidant) also may be protective against cancer. Analysis of health behavior and outcomes by acculturation data are needed among Asian subpopulations to enable us to better target health promotion efforts.

Ms. Evaon Wong-Kim stressed the importance of good data because the data are used to plan future programs. There is a need for information on immigrant status. How do we serve this population? How do immigrant populations differ from those populations who have been in the United States for generations? The United States has a large, diverse population which will allow us to examine protective and other factors among minority and medically underserved populations.

Dr. Reggie Ho provided an overview of the data issues with regard to Pacific Islanders. More than 80 percent of all Native Hawaiians are included in the SEER program (which reports incidence and survival data), but minimal cancer data for other Pacific Islanders are collected. Native Hawaiians make up 12-22 percent of Hawaii’s population and there are 72,272 Native Hawaiians who reside in the Continental United States. The indigenous status and health status of Native Hawaiians present problems that are distinct from those facing Asians. Issues raised by new and recent immigrants and refugees (e.g., languages barriers, increased prevalence of certain cancers with increased length of stay in the United States, and rare cancers) are not priority concerns for Native Hawaiians. The low incidence and mortality rates of breast cancer among Japanese in Hawaii masks (because of aggregate data) the fact that Native Hawaiians not only have the highest mortality rates due to breast cancer in the state, but they also rank third nationally, behind African Americans and Alaska Natives. Lung cancer morbidity and mortality are second highest among Native Hawaiians and breast cancer morbidity and mortality are second only to the white population. The morbidity and mortality rates among Native Hawaiians have increased dramatically over the past 30 years. Is this due to shift toward a Western lifestyle?

Although there is very little information available on non-Hawaiian Pacific Islanders, the CDC and the NCI have initiated efforts to address this data gap. **For example, the CDC is providing funding for a cancer registry in the Republic of Palau and the SEER program is collecting data on American Samoans in California and American Samoa. [Need to mention the Dale Hitchcock (?) report.]** Information is needed on these non-Hawaiian Pacific Islanders to understand the scope and breadth of the cancer burden in these communities. It also is needed to understand where and why disparate rates exist so that interventions can be developed to eliminate these disparities. Cancer is reported as a leading cause of death (in the top three) in all jurisdictions with the exception of the Federated States of Micronesia. In Guam, lung cancer accounts for one-third of all recorded cancer deaths. In the Republic of the Marshall Islands, tribal records report that lung and cervical cancers account for more than two-thirds of cancer incidences (between 1985 and 1994). Cervical cancer is reported to be 5.8 times higher in Marshallese females than in U.S. females. Links between betel nut chewing and certain oral cancers are suspected in countries where this is a wide practice (i.e., Federated States of Micronesia, Commonwealth of the Northern Mariana Islands, and Republic of Palau).

For most of the Pacific Islander subpopulations, there are no accurate numerators or denominators. Therefore, cancer rates cannot be calculated for these groups. With the exception of Hawaii, there are no

tumor registries in the states/territories where Pacific Islanders reside. One investigator has reported that cancer mortality in the Marshall Islands is worse than for any other group in the United States, including African Americans. The most prevalent cancers among Pacific Islanders are lung, cervical, head/neck (possibly related to betel nut chewing), and liver (due to high incidence of Hepatitis). **[Should look at DHHS report on Insular Territories and at the recent publication on cancer incidence in Chinese, Japanese and Filipinos in the United States and Asia, 1988-1992, from the California Cancer Center SEER.]**

Understanding cultural characteristics (e.g., health seeking behaviors) will enhance understanding or highlight problem areas. For example, the perception of health providers about Native Hawaiian women is that they seek care late, when cancers are less curable. Although this accounts in part for higher mortality rates, data show that for Native Hawaiian women diagnosed for breast cancer at stage 1, when survival rates are in the 90 percentile, mortality rates are still 50 percent higher than for non-Hawaiian women. Are these women not following through with recommended treatment? Are they offered the same options as non-Hawaiian women? Anecdotal information from case managers indicates that some physicians are less aggressive with treatment for non-Hawaiian women because they believe the women will not be compliant. Are physicians communicating the treatment options to the clients effectively? Hawaiians value their role and relationship to the family and extended family. Decisions are made in consideration of the whole versus the individual. This is believed to have an impact on the low accrual rates of Native Hawaiians in cancer clinical trials. A more effective approach to recruiting Native Hawaiians to these trials may be to ask for their participation because it will help the health care community understand the efficacy of new treatments, which will benefit other Hawaiians, rather than asking them to participate because they will receive free drugs or services. Understanding cultural beliefs and practices is important in determining how Native Hawaiians seek, accept, and utilize cancer care.

Although Hawaii is a designated SEER site and there is a Hawaii State Tumor Registry, it has been difficult to get data in understandable forms from these agencies for community use. Health care data from the Pacific Basin is generated from different sources including vital statistics (birth and death certificates), inpatient information (hospital discharge data), outpatient clinical data, public health clinic information (with special information regarding rates of, for example, Hansen's disease, sexually transmitted diseases, tuberculosis, immunizations, and prenatal care), dispensary data, indices of notifiable (reportable) diseases, and special data sources such as dental clinics, disabled children's services, and laboratories. Organizations that require and make use of this data include the health departments and local governments of each jurisdiction, several U.S. agencies, the World Health Organization, and the South Pacific Commission. There are a number of problems associated with collection of health status data, including:

- h Difficulties with data collection, particularly when births and deaths occur outside the hospital and country.
- h Data overload—too many forms and the collection of more data than can or are being used.
- h Lack of data consistency when outside groups or funders request new or slightly altered information.
- h Untrained or insufficiently trained data personnel.
- h Lack of appropriate hardware and software.
- h Unreliable power supplies.

There is a lack of behavioral risk factor data for Native Hawaiians and other Pacific Islanders. In Hawaii, the Department of Health collects household surveillance data similar to the NHIS. Approximately 3 percent of the total Hawaiian state population is surveyed door-to-door each year. However, these data are reported only as an aggregate group (all persons living in the state).

Nearly all Native Hawaiian and other Pacific Islanders could be considered medically underserved, in terms of the political and economic history of these conquered peoples. The income of Pacific Islanders is low and there is limited access to care. In the Pacific, jurisdictions where the United States has signed formal agreements to take care of the health and human service needs of the peoples, the health care infrastructure in these island nations is extremely poor, many health services are unavailable, and many simple procedures (e.g., Pap test) often are unavailable. For example, there are no functional mammogram machines in American Samoa; only Guam has the equipment to perform mammograms. In addition, there are no adequate pathology services in the Pacific Islands. Even when tests such as Pap smears are available, the specimens must be sent overseas to the United States or Australia to be interpreted and results often take months up to years to obtain. Because there are no cancer facilities on most Pacific Islands, individuals often are forced to travel overseas to obtain treatment. Obviously, the interval between testing and treatment negatively impacts the survival rates of those women who have advanced disease. **[Should get a comment from the NCI—and California—guided projects on cancer control needs among Native American Samoans.]**

In response to a question concerning whether researchers have looked at the differences between those Pacific Islanders living in the Continental United States and those living in Hawaii and other Pacific Islands, Dr. Ho indicated that some information needed to do such an analysis has been captured by the SEER program's registries in Hawaii, California, and Washington.

Dr. Hiatt indicated that the NCI is making some progress in addressing problems that concern expanding coverage of ethnic minority populations as well as those concerning numerators and denominators. However, there is some concern about disaggregation of data. The more you disaggregate, the smaller the cell size and the more unreliable the data. How do we resolve this tension? What data are needed given the reliability limitations? Dr. Hiatt also noted the importance of quality of care and the disparities among populations, particularly Pacific Islanders.

Several Working Group members responded that disaggregation is essential for ethnic minority populations as well as the white population. By 2003, the Census Bureau hopes to have covered the entire United States conducting interviews with one in six households to collect data on the social and economic characteristics of the household **(need to verify)**. A pilot has been conducted successfully to test this process; however, a number of methodological issues remain that must be addressed. Dr. Friedell pointed out that many homes in Kentucky do not have telephones (20 percent of homes in Appalachian counties do not have telephones); therefore, these households will be excluded from such a survey unless costly face-to-face interviews are conducted. Non-English speaking households also would be excluded from the survey.

Issues for Rural, Poor White, Medically Underserved (Appalachian) Populations—Dr. Gilbert Friedell and Ms. Pamela Brown

Dr. Gilbert Friedell stated that the age-adjusted cancer incidence rate for all cases of cancer in Kentucky (1996) was 420.2 per 100,000 population, while the age-adjusted rate for SEER (1995) was 392.0 per 100,000 population (see Table 3). The rates for lung, breast, and cervical cancer also were higher in Kentucky than the rates reported by SEER. Most of Kentucky's population resides in rural areas. The Appalachian area of Kentucky has the highest poverty rate and lowest education level in the state and the population is predominantly white.

There are a number of barriers to cancer screening, diagnosis, and treatment, including:

- h Poverty
- h Isolation
 - g Geographic
 - g Transportation
 - g Literacy
 - g Cultural
 - Fatalism
 - Male dominance
 - g Age
- h Fear
- h Acceptability (user-friendliness) of the service provided
 - g Physical arrangements, prolonged waiting time
 - g Staff attitudes
 - g Hours of service
- h Lack of continuity

Table 3. Age-Adjusted Cancer Incidence Rates Per 100,000 Population

Type of Cancer	KY 1996 Rate	SEER 1995
All Cases	420.2	392.0
Male - All Cases	493.4	460.1
Female - All Cases	373.5	344.3
Lung Cancer	83.5	55.9
Male - Lung	120.2	73.4
Female - Lung	55.9	42.6
Female Breast Cancer	113.0	111.3
Invasive Cervix Cancer	10.8	8.0

Dr. Friedell read the following quote from Carolyn Staley from the National Institute for Literacy:

“Literacy is more than reading and writing. It is the ability to access information, make decisions, and add to the overall quality of your life.”

He stressed the importance of utilization of health care services and pointed out that availability and access do not equal utilization. From an in-person 1986 survey of women in southeastern Kentucky who had a non-emergency medical visit within 3.5 years of the survey, the number who had a Pap smear in the previous 3.5 years declined significantly in women 50 and older (see Figure 4). These data indicate that even though access to a Pap test was available and women had visits annually to health care providers, many women 50 and older were not utilizing this service. Dr. Friedell noted that communication is a key to overcoming this lack of utilization.

In 1996, there were 831,191 individuals residing in the Louisville area, of whom 704,948 (84.8 percent) were white and 126,243 (15.2 percent) were Black. In Appalachia, there were 526,978 individuals, of whom 522,001 (99.1 percent) were white and 4,977 (0.9 percent) were Black. As presented in Table 4, the age-adjusted incidence (1995-1997) of lung cancer in Kentucky was 85.03 per 100,000 population (overall), 84.35 for whites, 97.18 for Blacks, and 98.25 for Appalachia. The age-adjusted incidence (1995-1997) of invasive cervical cancer was 10.99 per 100,000 women (overall), 10.82 for whites, 13.76 for Blacks, and 13.34 for Appalachia.

Figure 4. Percentage of Women with Medical Visit in Past Year and with Papanicolaou Smear in Past 3.5 Years

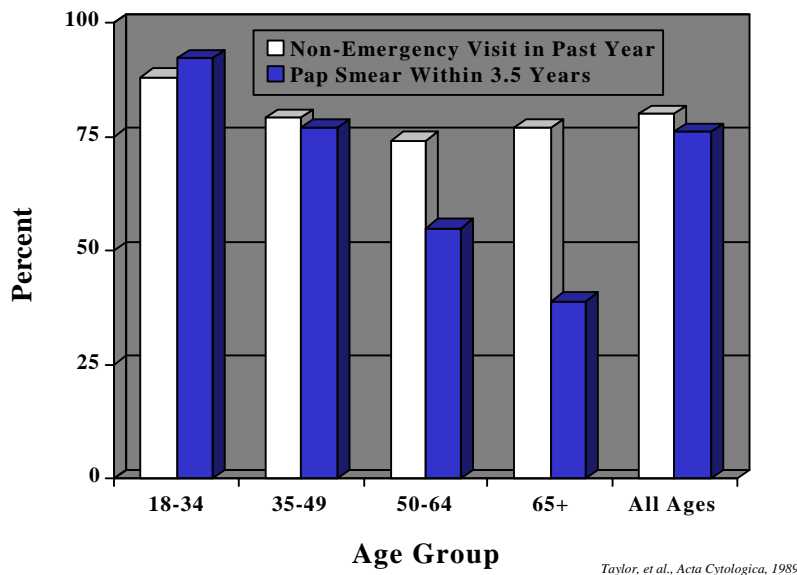


Table 4. 1995-1997 Age-Adjusted Cancer Incidence Rates Per 100,000 Population

Site	Kentucky Overall	Kentucky White	Kentucky Black	Appalachia 3 ADDS*
Lung	85.03	84.35	97.18	98.25
Invasive Cervix	10.99	10.82	13.76	13.34

* Big Sandy, Kentucky River, and Cumberland Area Development Districts

Dr. Friedell provided data from the Kentucky BRFSS (1988-1991) on the percentage of women having a Pap test in the past 2 years by geography, household income, and education level (see Tables 5 and 6). Fewer women in the Appalachian area, as compared to women outside the Appalachian area had received Pap tests in the past 2 years (72.5 percent versus 80.8 percent); fewer women in households with incomes of less than \$25,000 received Pap tests when compared to women in households with incomes of \$25,000 or more (80.3 percent versus 88.9 percent); and fewer women with less than a high school education received Pap tests in the past 2 years when compared to women with a high school education or more (67.8 percent versus 86.7 percent). The greatest variance occurs in the education level comparison. A similar analysis of BRFSS data for cigarette smoking shows that a higher percentage of individuals residing in the Appalachian area smoke cigarettes as compared to individuals living outside Appalachia (35.1 percent versus 30.9 percent); more individuals in households with incomes of less than \$25,000 smoke cigarettes as compared to individuals in households with incomes of \$25,000 or more (35.5 percent versus 26.5 percent); and more individuals with less than high school education smoke cigarettes as compared to individuals with a high school education or more (35.4 percent versus 26.8 percent).

Table 5. Percent of Women Having Pap Tests by Location, Income, and Education*

Percentage of Women Having a Pap Test in the Past 2 Years by <u>Geography</u>	
Appalachian Area (3 ADDs)	Non-Appalachian Area (12 ADDs)
72.5%	80.8%
Percentage of Women Having a Pap Test in the Past 2 Years by <u>Household Income</u>	
Less than \$25,000	\$25,000 or more
80.3%	88.9%
Percentage of Women Having a Pap Test in the Past 2 Years by <u>Education</u>	
Less than High School	High School or more
67.8%	86.7%

Table 6. Percent of Current Cigarette Smokers by Location, Income, and Education*

Percentage of Current Cigarette Smokers by <u>Geography</u>	
Appalachian Area (3 ADDs)	Non-Appalachian Area (12 ADDs)
35.1%	30.9%
Percentage of Current Cigarette Smokers by <u>Household Income</u>	
Less than \$25,000	\$25,000 or more
35.5%	26.5%
Percentage of Current Cigarette Smokers by <u>Education</u>	
Less than High School	High School or more
35.4%	26.8%

* Source: Behavioral Risk Factor Surveillance Survey for Kentucky (1988-1991)

Reduction in incidence and mortality in Appalachia for several cancers, particularly lung, will be a function of our success in achieving primary prevention regarding tobacco use and diet; and secondary prevention (i.e., screening) for cancers of the breast, cervix, and colon. In all of these areas, there is a need for individual behavior change, but this will happen primarily when it is in the context of a favorable social environment (statement to the President's Cancer Panel).

Ms. Pamela Brown provided an overview of the issues associated with rural whites and Blacks in West Virginia. The state's population is predominantly white (96 percent white and 4 percent other, of which 3.7 percent are Black). She indicated that melanoma and prostate cancer are under reported in the state because many of these individuals are not seen in hospitals and only some physicians report cases voluntarily. If these patients' laboratory tests are sent out of the state, these cases are lost to the registry. Individuals who receive

cancer screening are screened only for breast and cervical cancer. The registry currently collects data on African Americans, but not Hispanics, Asians, Native Americans, and migrant populations.

Information on occupation/industry should be collected by the registry to show relationships between mining/chemical industry and lung cancer. Although the registry is now collecting survival and treatment information, the data are not yet reliable and no information on treatment offered is collected. In West Virginia, late stage diagnosis and fewer lumpectomies are linked to rural, low-income patients. Few low-income, rural patients enter or are offered information on clinical trials. SES (e.g., income, education level, and literacy) information is important. The literacy rate is 40-65 percent in some counties; therefore, people cannot comprehend or understand many of the messages that are distributed by the health care community. In West Virginia, education level may not be a good indication of literacy. A survey was conducted several years ago of high school graduates and students who had completed the eighth grade; both groups were identical in terms of literacy. Residents of West Virginia do not necessarily seek treatment for cancer and they may be more likely to choose “folk remedies” or to see local providers only. Rural physicians may not be aware of the “standard treatment” and they are reluctant to refer patients to a medical center.

The West Virginia Cancer Registry at the Bureau for Public Health has collected data on all cancer cases, with the exception of basal cell and squamous cell carcinomas of the skin, diagnosed in residents on or after January 1, 1993. Reporting sources include hospital-based cancer registries, hospitals without cancer registries, freestanding pathology laboratories, freestanding radiation treatment centers, clinics, nursing homes, and physicians. The registry has reciprocal agreements for data exchange with registries in 15 states. The West Virginia Cancer Registry has >96 percent completeness of cases based on NAACCR criteria; therefore, it meets the “silver standard” level for completeness. The registry has been certified for only the last 2 years; therefore, the data may not be totally reliable at the present time. Administrators and researchers cannot get quick access to registry data because of personnel shortages. The registry needs more competent data managers and other technical support staff to collect and enter data. Hospital-based registry personnel have varying skills and training opportunities, and West Virginia has difficulty recruiting experienced epidemiologists. There is a rule before the West Virginia Legislature to require hospitals with >50 beds to submit data to the registry, but at the present time, hospitals are only doing so on a voluntary basis. This means that information about rural, medically underserved patients is under reported because they are more likely to go to small, local hospitals. About 20-40 percent of the West Virginia population is medically underserved as defined by having a household income below the federal poverty level, distance to a hospital, residing in a rural area, and the number of physicians in the county of residence.

There is a need to geocode the data collected by the registry. Census tracking information in a rural state is not as enlightening because so many addresses are P.O. Boxes, General Delivery and many rural Post Offices cover multiple counties. In addition, causes of death often are misclassified and cancer may not be listed as the underlying cause of death on the death certificate. It may take 12 months to receive data from bordering states on patients who go out-of-state for treatment. Another limitation is that the registry currently is able to collect data down to the county level only on breast, prostate, lung, and colorectal cancers. If the registry collects data on all cancers at the county level, trends could be more clearly identified and linked to Census data. Links need to be established between cancer data and patient education and income to describe the cancer burden among the white population.

Capacity building also is needed—we need to create more opportunities to improve the competence of staff collecting data for cancer registries. Accurate data collection is critical and good registries are essential.

Dr. Henderson commented that the low rates for Pap testing among Appalachian women may be related to the lack of women health care providers available to perform the test. He pointed out that in a study of

Native American women in South Dakota, North Dakota, Minnesota, Michigan, and Wisconsin, researchers found that the rate of Pap testing increased dramatically when female nurses were trained and made available to take the samples.

Socioeconomic Status—Drs. Gilbert Friedell and Gopal Singh

Dr. Gilbert Friedell referred to data that indicated that the influence of education and income on the use of both breast and cervical cancer screening is not direct, but rather works through the association of these SES variables with other factors. At least for rural women, simply providing free screening services to low-income women will not increase significantly the utilization of cancer screening services. There is a need to develop appropriate, effective professional education interventions to increase physicians' recognition of the role they play in women's cancer screening behavior.

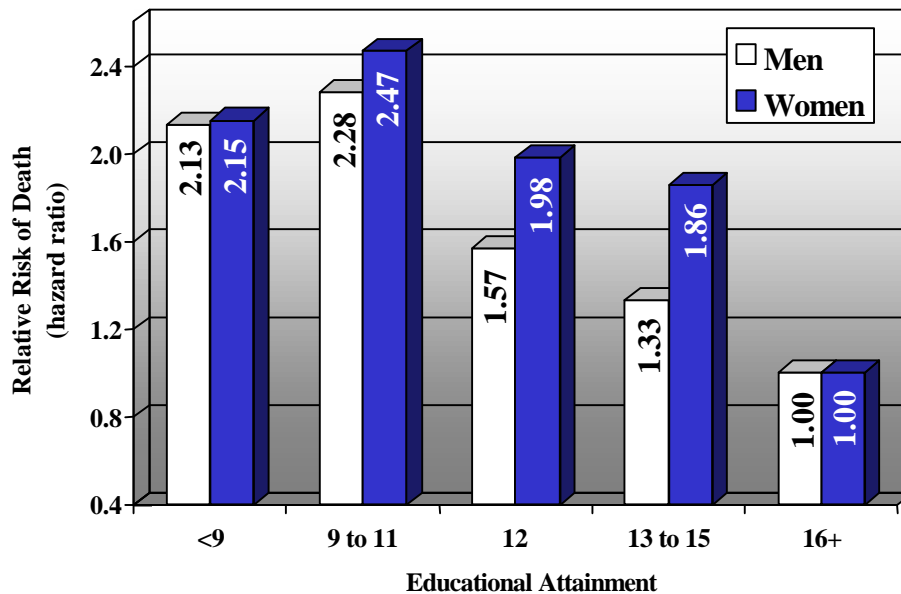
Dr. Hullett indicated that her results differed from those obtained by Dr. Friedell. She found that even when health care providers take the time to educate the patient about the importance of a Pap smear, many of the patients did not make an appointment for the test. She noted that SES variables often are surrogates for other items, such as transportation.

Dr. Friedell asked how we get SES data into the record. Should physicians/health care providers include SES information in the medical record? Dr. Williams responded that, as a practicing physician, she has only 15 minutes per patient; therefore, she does not have the time to collect SES data. Dr. Jones responded that the SES data should be collected by hospitals, but unless we convince them of the importance of such information it will not be collected because of the labor required. Consideration must be given to the type of setting in which a patient would feel most comfortable providing that information. Dr. Jones noted that persons in lower SES strata have increased exposure to a broad range of psychosocial variables predictive of cancer morbidity and mortality.

Dr. Gopal Singh described some of the data issues related to obtaining SES data on a national basis. The SEER program is involved in a number of SES-related projects, including efforts to link incidence and mortality data to Census data as well as initiatives to collect SES directly through the Current Population Survey and link to the National Death Index, and other surveys. What is SES? It is a multidimensional concept including both social and structural measures. SES information includes measures of social position, such as education, occupation, wealth, home ownership, job security, financial security, social prestige, and social connections. Dr. Singh presented data on lung cancer mortality among U.S. men and women by education (see Figure 5). The relative risk of death is higher for women who have less than 16 years of education when compared to men with the same education level. The difference between men and women disappears for those with 16+ years of education. As depicted in Figure 6, lung cancer mortality is significantly greater for U.S. men aged 65+ years when compared to men aged 25-64 years for family incomes of up to \$49,999 (1980 dollars). This difference declines for family incomes of \$20,000-\$49,999, and disappears completely for the two age groups of men when the family income is \$50,000 and more. Figures 7 and 8 depict the covariate-adjusted occupational differentials and the covariate-adjusted industry differentials (respectively) in lung cancer mortality among U.S. men aged 24-65 years (National Longitudinal Mortality Study, 1979-1989). Figure 7 indicates that the unemployed/outside labor force, transport equipment operatives, and sales workers have the highest hazard ratios for lung cancer mortality among occupations. Figure 8 indicates that personal services, construction, finance/insurance/real estate, and transportation/communications/ public utilities have the highest hazard ratios among industries.

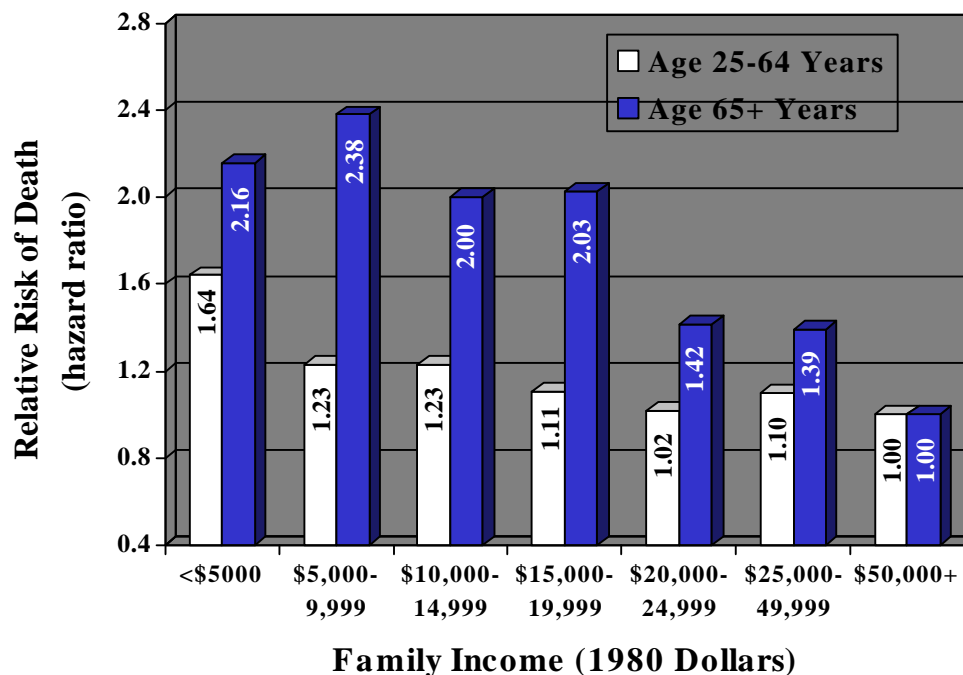
Dr. Singh presented a graph of the average annual age-adjusted cancer death rates (1988-1992) for men in selected racial/ethnic groups, including white, Black, American Indian, Chinese, Japanese, Filipino, and Hawaiian (see Figure 9). For all cancers combined as well as digestive, respiratory, and prostate cancers, Black and Hawaiian men had the highest death rates. For urinary cancers, white men had the

Figure 5. Lung Cancer Mortality Among U.S. Men and Women Aged 25-64 Years, by Education (Cox Model)
National Longitudinal Mortality Study, 1979-1989



Adjusted for age, ethnicity, marital status, place of residence, immigrant status, occupation, and income (n=145,132 men & 156,755 women). All significant at p<0.05.

Figure 6. Lung Cancer Mortality Among U.S. Men Aged 25-64 & 65+ Years, by Family Income (Cox Model)
National Longitudinal Mortality Study, 1979-1989



Adjusted for age, ethnicity, marital status, place of residence, immigrant status, education, and occupation (n=145,132 & 28,713). All significant at p<0.05.

Figure 7. Covariate-Adjusted Occupational Differentials in Lung Cancer Mortality Among U.S. Men Aged 25-64 Years: National Longitudinal Mortality Study, 1979-1989

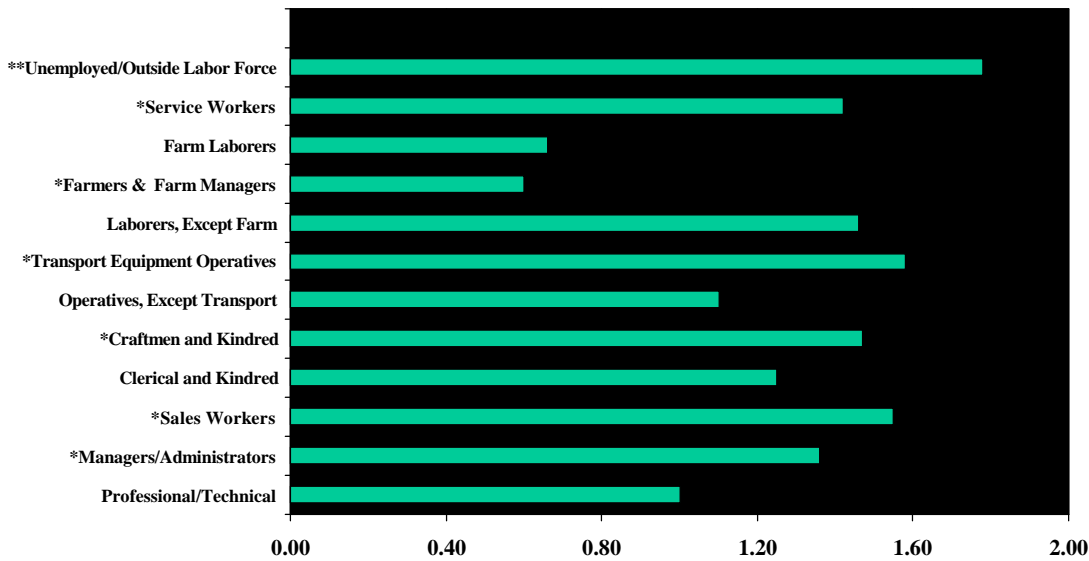
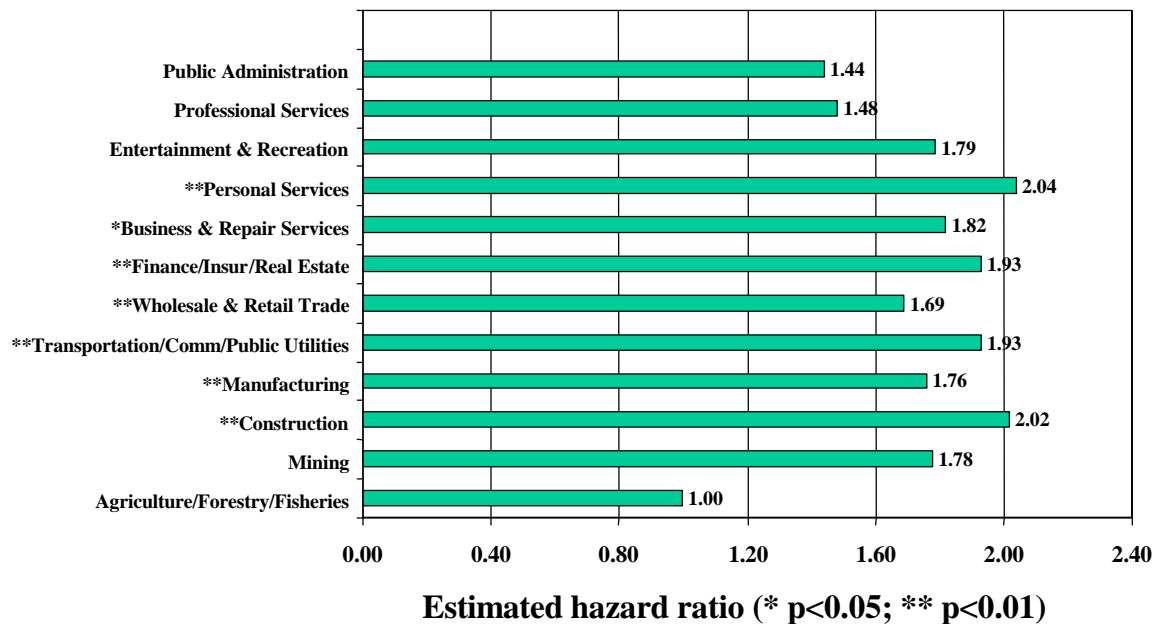


Figure 8. Covariate-Adjusted Industry Differentials in Lung Cancer Mortality Among U.S. Men Aged 25-64 Years: National Longitudinal Mortality Study, 1979-1989 (N=145,132)



highest death rate, but Black and Hawaiian men were close behind. Dr. Singh presented a similar graph for women in selected racial/ethnic groups (see Figure 10). For all cancers combined, Hawaiian women had the highest death rate followed closely by Black and white women. For digestive, respiratory,

Figure 9. Average Annual Age-Adjusted Cancer Death Rates for Men in Selected Racial/Ethnic Groups: United States, 1988-1992

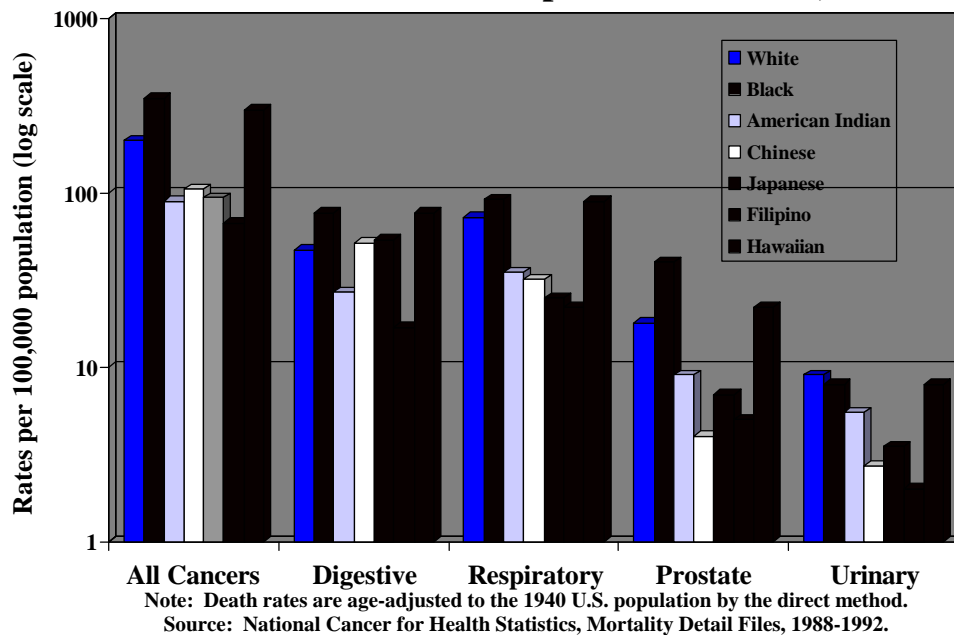
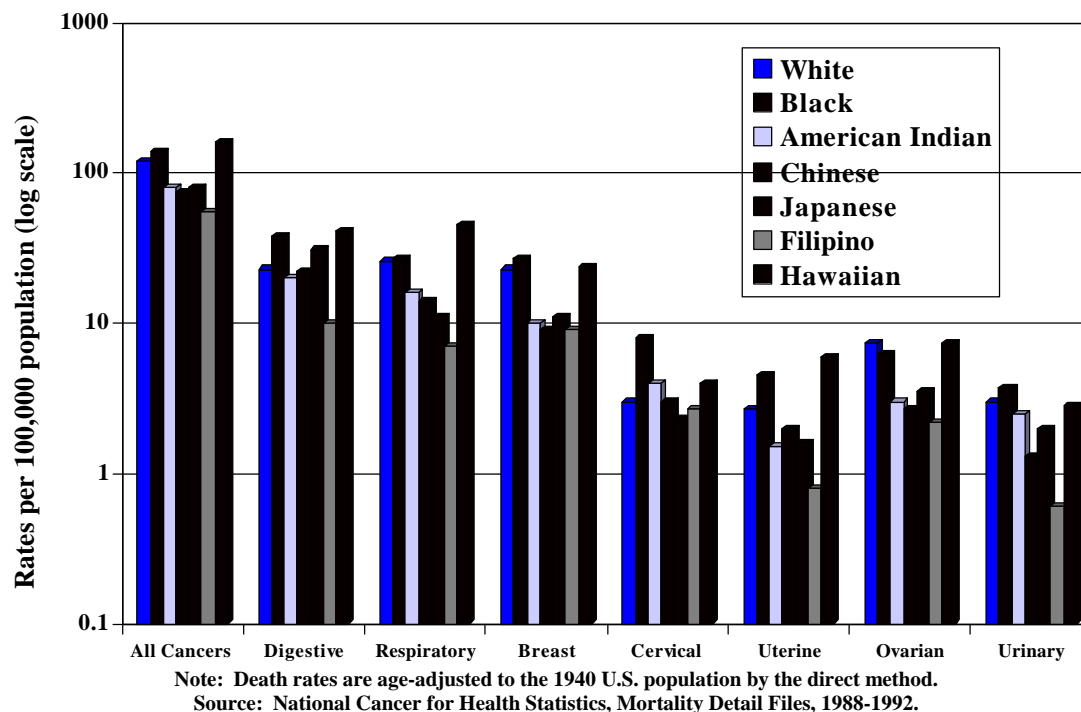


Figure 10. Average Annual Age-Adjusted Cancer Death Rates for Women in Selected Racial/Ethnic Groups: United States, 1988-1992

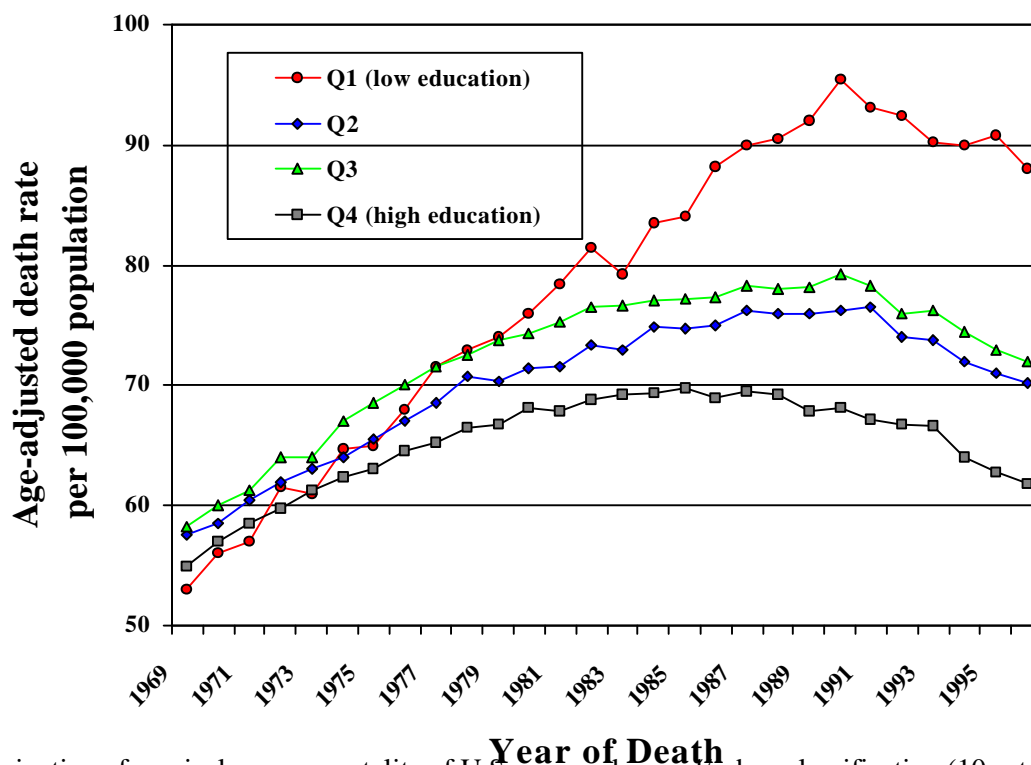


breast, and uterine cancers, Black and Hawaiian women had the highest death rates; for cervical cancer, Black and American Indian women had the highest death rates; for ovarian cancer, white and Hawaiian

women had the highest death rates followed closely by Black women; and for urinary cancer, Black women had the highest death rates followed closely by white and Hawaiian women.

Examination of lung cancer mortality data for men by education level indicates that death rates are highest for men with the lowest level of education and lowest for men with the highest level of education. However, this does not hold true for women (see Figure 11). The highest death rate is among women with higher education levels and lowest among women with lower education levels (see Figure 12). Examination of lung cancer mortality among U.S. men by county SES status (derived from 1990 Census data on education, income distribution, occupation, wealth, unemployment, and housing condition) indicates that death rates decline as SES status increases (see Figure 13). Examination of cervical cancer mortality in U.S. women by county SES status indicates that the relative risk of death (adjusted for age, ethnicity, and rural/urban) declines with increase in SES status (see Figure 14).

Figure 11. Lung Cancer Mortality Among U.S. Males by Education Level, 1969-1996



Examination of cervical cancer mortality of U.S. women by rural/urban classification (10 categories from most urban to most rural) indicates that women in the most rural areas have the lowest relative risk of death (see Figure 15). However, there is no continual increase in relative risk of death from most rural to most urban (no linear effect).

Dr. Henderson pointed out that these data are subject to diagnosis bias. In addition, the cause of death is often misclassified (i.e., cancer is not always noted as the cause of death on the death certificate). One participant asked why there was no data for Hispanics on Dr. Singh's graphs. Dr. Singh replied that these graphs were based on 1990 Census information, **which did not require states to report death data**

Figure 12. Lung Cancer Mortality Among U.S. Females, by Education Level, 1969-1996

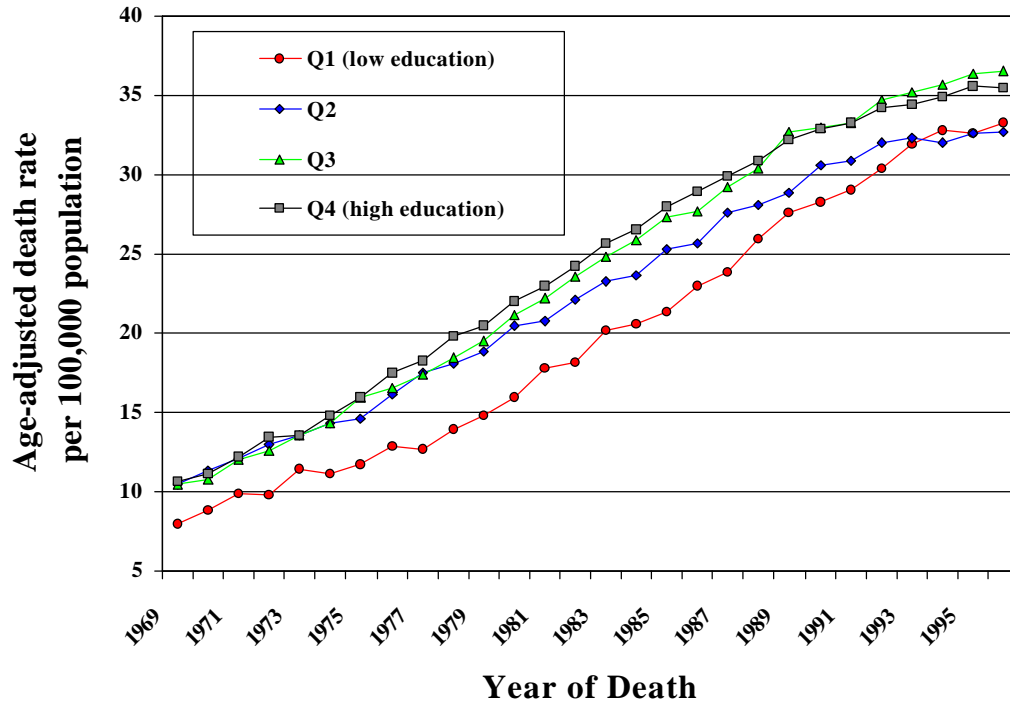
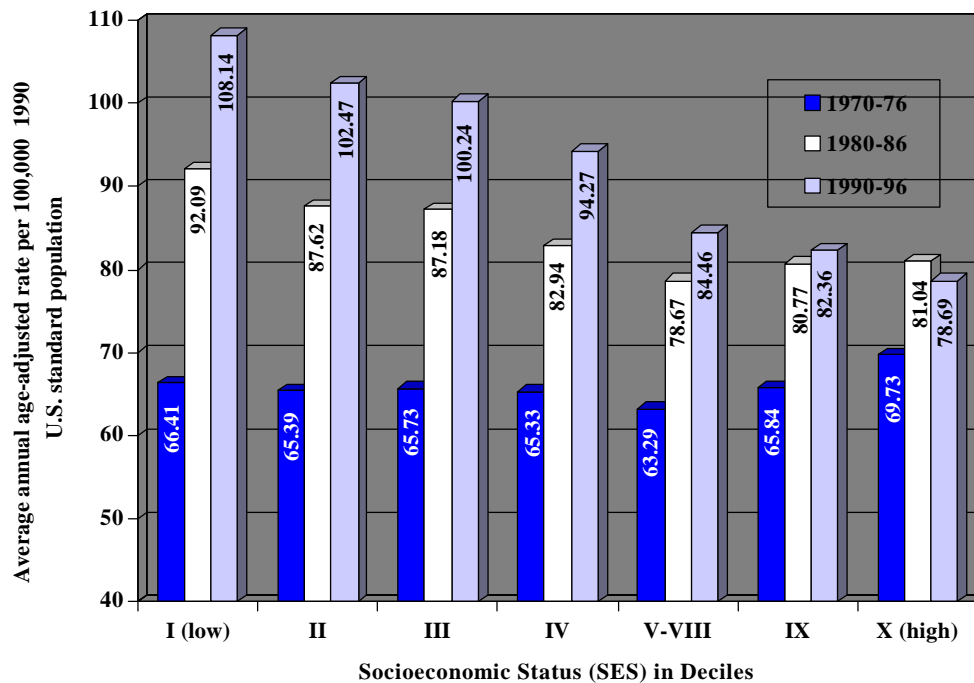
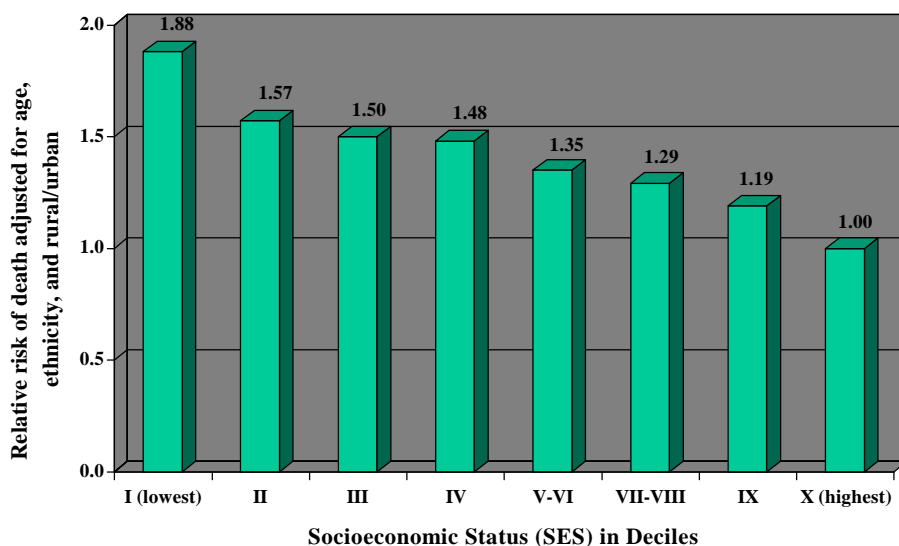


Figure 13. Lung Cancer Mortality Among U.S. Males, by County Socioeconomic Status, 1970-1996



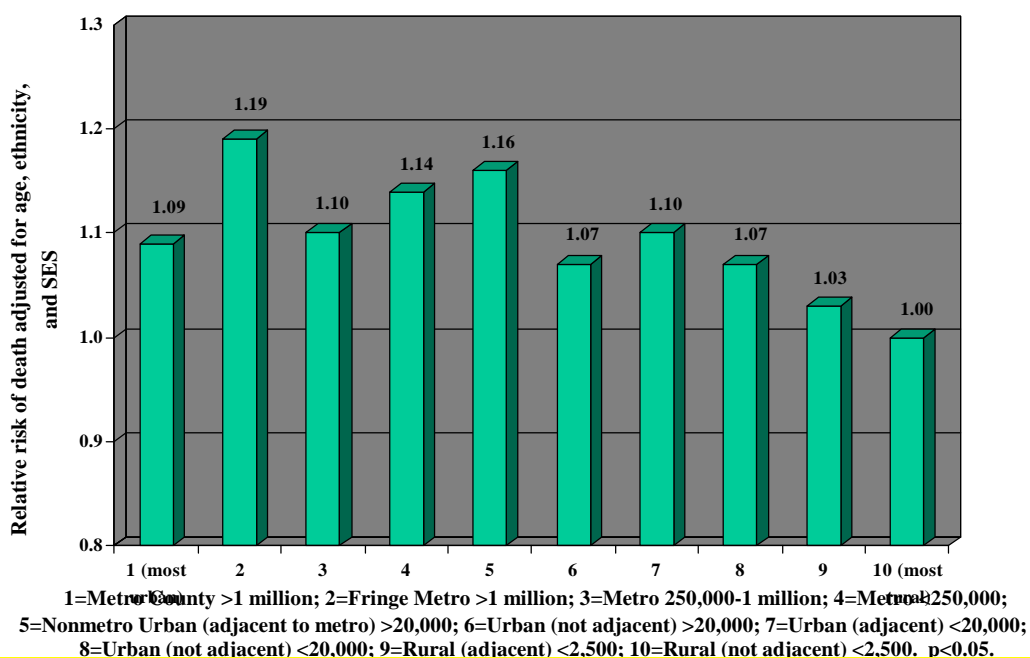
SES, a factor-based scale, is derived from 1990 Census data on education, income distribution, occupation, wealth, unemployment, and housing condition (n=2,753 counties). All relative risks are significant at p<0.01.

**Figure 14. Cervical Cancer Mortality of U.S. Women,
by County Socioeconomic Status, 1990-1996
Poisson Regression Model**



SES, a factor-based scale, is derived from 1990 Census data on education, income distribution, occupation, wealth, unemployment, and housing condition (n=3,095 counties). All relative risks are significant at $p < 0.01$.

**Figure 15. Cervical Cancer Mortality of U.S. Women,
by 10-Category Rural/Urban Classification, 1990-1996
Poisson Regression Model**



classified by Hispanic origin (such information was not required by each of the 50 states until the early 1990s). However, some states did report that information on the death certificate in 1990; therefore, we

have some data but not for all 50 states. Dr. Hampton mentioned that American Indians often are misclassified on their death certificates. Dr. Singh responded that this would have had no effect on the data in his graphs because those are based on the self-report in the original survey, not the death certificates.

Dr. Friedell noted that Dr. Singh's presentation pointed out the limitations of our data—we cannot assume that one factor drives the outcome. His data demonstrate the complexity of the issue. To what degree is ethnicity a proxy for the more immediate variables? The answer to this question will impact the data we collect. Because there is a move toward collecting less data, we need to identify what information would be most useful to collect.

Data Collection Needs and Challenges—Drs. LaMar McGinnis, Hannah Weir, and Mr. Barry Miller

Dr. LaMar McGinnis pointed out that the American Cancer Society (ACS) has established some challenging goals for 2015 to reduce cancer mortality and incidence and to improve the quality of life of cancer patients. This cannot be accomplished unless we understand the cancer burden in each group of society. Why is it so difficult to collect data given that we now have computers to assist in the process? How are we going to collect meaningful, accurate data using our present system? Everyone agrees that we need to know more than just incidence and mortality. The ACS and other organizations are spending substantial amounts of money to collect data, but we need to move beyond incidence and mortality data. There is a need for reliable, useful, unbiased data that can be shared with the public to assist them in making their own decisions about cancer care. **A 1998 collaborative publication from NCI, ACS, NAACCR, CDC, and others** discussed the feasibility of a national surveillance system, and the National Coordinating Council for Cancer Surveillance is developing a report on a National Surveillance Framework for Cancer. The Data Working Group should determine what data would be most useful. We also need to develop some definitions that could be widely applied. For example, what does culturally appropriate mean? What is SES and how is it measured? What information is not presently available through SEER and state registries that would be helpful? The lack of accurate denominators is a problem. Since 1973, the SEER program has collected detailed ethnic information; therefore, we have numerator data for many ethnic minorities throughout the reporting period.

The budget for the BRFSS study to collect data on risk factors has increased. Does this study collect adequate information on the ethnic minorities and medically underserved groups living in the United States? **How do you combine and compare BRFSS data across many states when each employs a similar but different survey design?** Because the BRFSS is a telephone survey, does it adequately cover the medically underserved population groups (e.g., Appalachia)? What about the increasing use of cell phones in lieu of traditional phones? Are we missing segments of the population by relying on surveys administered through traditional technology (e.g., telephones)? The new Census survey has six categories for race and individuals completing the survey can check all that apply. If an individual checks multiple categories is that individual counted several times? It might be useful to have a presentation on how the Census Bureau plans to handle this issue. Dr. Singh pointed out that because the Census will ask for information on Hispanic origin as well as ethnicity, there should be a more accurate counting of the U.S. Hispanic population. Ms. Patricia Golden responded that collection of both race and ethnicity information may complicate the counting process.

Dr. Hannah Weir provided an overview of CDC's surveillance activities. In 1994, the CDC began funding state registries through the NPCR program. She described and distributed copies of the National Program of Cancer Registries: Cancer Surveillance System Rationale and Approach document outlining

CDC's rationale and planned approach for receiving, assessing, enhancing, aggregating, and disseminating cancer data from the states funded by the NPCR. Dr. Weir described the activities of the NAACCR Certification Committee, of which she is currently the chair. NAACCR has established a process by which NAACCR member registries can receive objective evaluation of their performance in critical areas of cancer registration: completeness of case ascertainment, quality and completeness of data collected, and timeliness of the data. SEER provides incidence rates by which to assess the overall completeness of case ascertainment of non-SEER registries. Dr. Weir described how NAACCR awards Gold or Silver Certificates to registries that meet the following performance standards:

	<u>Gold Certificate</u>	<u>Silver Certificate</u>
1. Completeness of Case Ascertainment	≥95%	≥90%
2. Percent Death Certificate Only Cases	≤3%	≤5%
3. Percent Records Passing EDITS	≥99%	≥97%
4. Percent Missing Data		
Age	2%	3%
Gender	2%	3%
Race	3%	5%
County of Residence	2%	3%
5. Timeliness	Data available within 24 months of the close of the diagnosis year	Data available within 24 months of the close of the diagnosis year

Data from registries meeting standards are combined in the pooled estimate of cancer as published in NAACCR's Cancer in North America. All SEER registries meet the NAACCR data standards and were awarded Certificates. Data from NPCR states are of variable quality and completeness, but there has been improvement. In 1995, the first year for which NPCR states received funds to collect cancer data, 9 states were certified out of 28 that submitted data. In 1996, 15 states were certified out of 32 submitting data.

At Dr. Friedell's request, Dr. Weir presented a letter from Dr. Vivien Chen, describing the activities of the NAACCR Comparative Research Working Group (CRWG). Dr. Chen asked that the working group identify gaps in the data and any information needs. The four objectives of the working group are to: (1) identify gaps in current estimates of population groups, (2) identify immediate and long-term needs and future directions, (3) establish criteria for data quality, and (4) perform comparative analyses. The working group currently is addressing the comparability of the classification of Hispanics in various registries. Future plans include collecting and evaluating data from NPCR registries. This indepth, programmatic review will be designed to help the registries improve their quality and timeliness as well as assist them in implementing enhancements (e.g., geocoding data) and disseminating information to those who need it.

Ms. Shinagawa asked if the CDC had any plans to open registries in the Pacific Islands. Dr. Weir replied that the territories are eligible for funding and CDC encourages them to apply. Dr. Ramirez commented that the working group should develop a standard way of reporting Hispanic origin. Note: The NAACCR has established standards, and the CRWG is addressing current registry procedures for improving Hispanic data. Dr. Jones noted that there are very few minorities involved in collecting and analyzing cancer data for these registries.

Dr. Friedell asked how CDC's national surveillance system will relate to the SEER program. Which organization is ultimately responsible for cancer surveillance? He expressed his hope that the NCI and the CDC are working together to prevent the creation of two redundant systems. Dr. Friedell also pointed out that these national expenditures should facilitate better local use of data. Good data are

needed at the local level. Ms. Golden mentioned that another challenge at the state level is identifying the appropriate partners, which may vary from state to state. Dr. Friedell noted that, if federal funds are used, federal oversight of state registries may be necessary to ensure commonality and compatibility. Dr. Williams asked how the state registries were collecting the information. Dr. Weir responded that the information was collected from multiple sources. She noted that the CRWG will develop recommendations for collecting ethnicity and other data by 2002. The CRWG has just had its first teleconference so there is an opportunity to have input into the recommendations. Dr. Weinberg asked if federal staff participate in data collection at the local level. Dr. Weir responded that there are a number of CDC staff who are certified tumor registrars; these individuals travel all over the country training other registrars. Mr. Miller indicated that the NCI also has a tumor registrar who provides similar training. **Note: The American College of Surgeons requires cancer registries to meet standards established for approval by their Commission on Cancer. Most population-based registries utilize local hospital data as a source of information.** Dr. Weinberg replied that the federal staff must be involved to understand the barriers and complexities of data collection at the local level. Ms. Dunlap pointed out that these types of issues will be discussed at the November meeting. To involve the community in the data collection process, the community has to be integrated into the data collection system. **How can this be accomplished?**

Mr. Barry Miller described some of the information needs and data gaps that have been identified by the NCI. He indicated that the Institute is just starting to mine some of the information that is available. One effort is focused on improving the Arizona American Indian cancer data so that they can be reported by SEER. There are plans to compare these data with those for New Mexico American Indians and Alaska Natives. The NCI also is pursuing SEER linkages with the National Longitudinal Mortality Study as well as linkages to Census data. The Census tract SES information is useful and developing linkages between that data and SEER data has helped uncover relationships between SES and cancer rates. There are plans to examine all racial groups. By developing linkages between the SEER data and Census tract data, information on stage, tumor grade, tumor size, ethnicity, and SES parameters will be available for SEER sites. However, information on access and screening offered will not be available and this information could be very useful. The NCI has funded a SEER special study to collect additional, more detailed treatment information, such as specific chemotherapeutic agents, obtained from hospitals and physician contacts to answer specific research questions and to assess the quality of routinely collected treatment data.

Ms. Golden asked if these linkages were based on the 1990 Census. Mr. Miller responded that they were, but they will be updated with the 2000 Census data. He noted that some SEER registries were using old Census tract codes and others were not recording Census tract data. With regard to dissemination of data, Mr. Miller pointed out that there is a large amount of data and a number of tools available on the SEER Web Site. One of these tools is a mapping program that generates color maps of cancer death rates in a particular area. The NCI plans to provide a similar tool that will do this for incidence data. A group of statisticians are working to develop methods for analyzing the data—adjusting for correlations and spatial issues.

Data Needed to Mount Effective Cancer Control Activities for and by Ethnic Minorities and the Medically Underserved—Dr. Armin Weinberg

Dr. Armin Weinberg posed the question: Who uses the data? There are numerous data users including scientists, health care providers, teachers, the public, interested organizations, media, government, and industry. The data are used for research, application (e.g., treatment, screening, detection, diagnosis, prevention), policy, and management. Dr. Weinberg pointed out that people often do not really understand how to use the data and the limits of such data. Both professional and lay individuals access the data. Many individuals do not understand the data and their limits because they read only abstracts

and executive summaries of articles, papers, reports, and other publications. Methodologies often are misunderstood and statistics, charts, and graphs are often misread. Dr. Weinberg stated that we often overestimate the ability of individuals to understand and interpret data displays. A baseline against which to measure change is needed. There is a need to develop guidelines and recommendations based on the best data available (even though there are some data gaps). There also are a number of issues that need to be addressed including reimbursement issues and public agency positions and policies. Dr. Weinberg provided the following real examples of current dilemmas and problems:

- h Framingham study (non-representative of U.S. population)
- h The number “one” (people want to know about themselves)
- h BRFSS (telephones and response rates)
- h Random samples (for cancer registries?)
- h The cost of change
- h Smoking initiatives
- h Socioeconomics and science
- h Focus of programs and resources
- h Shifting locations of cancer care.

We need to define what is required in terms of data collection, keeping in mind that each of us has a different perspective. There is a cycle of dependence in that if there are limited data, it is difficult to define what we want. There also is a need to speed up the publication process. We need to address the various barriers to application by end users and there is a need for data on the application of data.

Linkages should be established in a timely and appropriate manner. For example, links should be made among cancer registries and the BRFSS at the state level. Feedback loops also are needed for data collection and use. Priorities must be established and national versus local needs must be balanced. We need to address the data collection issue now because if we do not there will be a decline in public trust, patient care will be compromised, and everyone will eventually find out that the data we currently have are of limited value. Although anxious to help publicize cancer information, the media does not know which messages to believe. Furthermore, media messages can influence how the public as well as researchers think. Finally, we need to develop innovative approaches and techniques that are expected from a high tech world.

Dr. Jones noted that there is a continuum of data needs. Some issues relate to one end of the spectrum, others to the other end, and some to the whole spectrum. There is a need to develop some conceptual frameworks. For African Americans, more data is not the answer. We have documented the problem over and over again. We need to know how to address the data and monitor the changes. Education and information dissemination are the keys for reducing the cancer burden among African Americans. Training of data collectors is needed as well as more African American data collectors.

Dr. Ho asked if we need to collect information on acculturation rather than race and ethnicity. Dr. Williams responded that they collect responses to 10 questions that relate to acculturation. She noted that culture traditionally has been transmitted by the mother; however, with dual income households, it is now being transmitted by the grandmother. Dr. Friedell asked the Working Group members if data on acculturation should be collected. Ms. Golden responded that diet and other risk factors are of greater concern; we are not concerned about whether an individual’s diet is related to his/her culture. If we focus on acculturation, we will be asking the wrong questions. The lifestyle of a group or individual is of more interest than acculturation information. There was consensus among the Working Group members that race and ethnicity data should be collected along with information on lifestyles. Dr. Hampton pointed out that there are some ethnic groups who have high risk behavior that is based on their culture. Dr. Ho commented that race and ethnicity will become less meaningful as races intermarry. If such a trend

continues, there will be no scientific basis for race. Therefore, we need to determine if there are data needed to understand cultural differences. Dr. Jones questioned whether such an idea was practical at the present time.

Dr. Williams indicated that it is important to understand the difference between race and culture—race is biology and genetics, and culture is lifestyle, language, dress, diet, music, etc. She also noted that it is easier to ask a patient their country of origin than their race. Individuals are more insulted if a data collector incorrectly assumes their race in lieu of asking them to self report their race. Self identification is the best approach. We need to collect data on country of origin. Dr. Jones stressed the need to continue to collect race and ethnicity data. Ms. Wong-Kim pointed out that many hospitals have stopped recording race; instead, they are recording data on ethnicity or cultural heritage. These data give the physician some insight into the patient’s lifestyle practices and views concerning medicine. Dr. Weinberg pointed out that race should not be the first question; maybe it should be further down the list of questions and the more important questions should be up front. Another data deficit is medical history. There is a need to teach the health community to record data on medical history.

Dr. Hampton noted that there are a number of barriers to utilization of health services including fear, poverty, lack of transportation, fear of a cancer diagnosis, etc. In an effort to protect the patient, translators, who typically are related to the patient, often fail to give the patient all of the “bad” news from the physician. We need to concentrate on training data collectors.

Dr. Friedell summarized the discussion by stating that data must be collected on race, ethnicity, and cultural heritage. Ms. Wong-Kim added that self identification is important. Such identification would help disaggregate data on Asians and Pacific Islanders, which have been grouped for the 2000 Census.

Recommendations of the ICC Data Working Group

Based on the presentations and discussions, the ICC Data Working Group developed the following recommendations to address data gaps for ethnic minorities and the medically underserved.

Recommendation 1: Socioeconomic status information should be collected for cancer patients.

As an approximation of SES, the following data should be collected for each case of cancer:

- h Insurance (secondary insurance, if any, in cases insured by Medicare)
- h Income
- h Education
- h Occupation/Profession (current or complete history?)

This information should be collected in medical records.

Recommendation 2: Meaningful numerator/denominator statistics must be developed.

Meaningful “denominator designations” must be developed that are compatible with the realities of cancer data collection, analysis, and utilization in effective cancer control efforts.

Recommendation 3: Methods must be developed for overcoming data collection communication barriers.

Methods must be developed and used for overcoming data collection communication barriers, such as:

- h Language problems (native/foreign language speakers, literacy)
- h Fear (of disease, of revealing personal information)
- h Patient-practitioner incompatibility (e.g., attitudinal differences).

Recommendation 4: Nativity data should be collected.

Data must be collected concerning native or immigration status (recent versus older status, e.g., number of generations identified), tribal designation if American Indian (for both federal and state recognized tribes), indigenous status (e.g., Native Hawaiian, Pacific Islander), and specific territorial residence or place of origin.

Recommendation 5: Cancer data should be collected in a disaggregated manner.

Data must be collected and analyzed in a “disaggregated” manner to preserve the original ethnic, American Indian tribal, or country/territorial origin of Asians and Pacific Islanders, recent immigrants, and other recognized groups. “Disaggregated” data can be later aggregated, but data collected in aggregate cannot later be “disaggregated” in a meaningful fashion.

Recommendation 6: The community should be involved in data collection.

To resolve data collection and analysis issues concerning “special populations” (e.g., Hispanics/Latinos of different national origins), appropriate (e.g., knowledgeable) representatives of the population in question must be involved.

Recommendation 7: Training of epidemiologists and related professionals from minority and medically underserved populations should be conducted.

To achieve the most effective data collection and analysis for “special populations,” training of epidemiologists and other professionals in related fields from these populations must be undertaken. These professionals have the community perspective that is critical to improving data collection.

Recommendation 8: A coordinated approach should be developed for collecting and analyzing risk factor information.

A coordinated, comprehensive approach for collecting and analyzing individual and societal behavior risk factor information should be developed. Such studies should involve appropriate communities in the collection and evaluation of the data.

Recommendation 9: SEER should be expanded to include collection of cancer data for all ethnic minorities and the medically underserved.

As recommended in the IOM Report, *The Unequal Burden of Cancer*, the SEER program should be expanded to include: lower-income or poverty-level whites, particularly those living in rural areas such as Appalachia; Hispanics/Latinos of all national origins; African Americans living in rural communities, particularly in the South; the culturally diverse American Indian populations; and all subgroups of Asians and Pacific Islanders.

Recommendation 10: CDC should improve the data collection efforts of state tumor registries.

As recommended in the IOM Report, the CDC (through the NPCR or other means) should elevate to its highest priority the development of “a reliable database on cancer for each state to serve as the basis for both the initiation and evaluation of cancer control efforts in those states.”

Longitudinal, population-based tumor registries, which include treatment data (for both standard and complementary alternative treatments), should be developed to produce meaningful data concerning cancer survival, especially in ethnic minorities and the medically underserved.

Recommendation 11: Federal agencies collecting cancer data should be mandated to collaborate to provide comprehensive national data.

The CDC’s second priority should be to continue to work with SEER, NAACCR, and the state registries to produce a truly national data set on cancer in ethnic minorities and the medically underserved as recommended in the IOM Report.

Recommendation 12: Persons from the community being studied should provide advice on culturally appropriate cancer control materials and instruments.

The definition of “culturally appropriate” must come from individuals in the community of “special populations” because they have the unique knowledge needed to gain access to the community and assure its protection. Thus, the definition of culturally appropriate will vary from community to community.

Recommendation 13: Special populations with low incidence of cancer should be studied for “protective factors.”

Approaches must be developed to assess the “protective factor(s)” that could explain the low incidence of certain cancers in particular populations.

It is anticipated that the participants of the November meeting will determine how to implement these 13 recommendations and develop a schedule for their implementation.

Appendix A:

List of Participants for the September 25-26, 1999 Data Working Group Meeting

Data Working Group Meeting Participants September 25-26, 1999

Co-Chairs:

Gilbert Friedell, M.D.

Markey Cancer Center
University of Kentucky
Lexington, KY

James Hampton, M.D.

Troy Dollie Smith Cancer Center
Oklahoma City, OK

Working Group Members:

Dileep Bal, M.D.

Chief, Cancer Control Branch
California Department of Health Services
Sacramento, CA

Reggie Ho, M.D., Ph.D.

Director, Straub Clinic and Hospital
Clinical Professor of Medicine
Division of Oncology
University of Hawaii
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Pamela Brown, M.P.A.

Director of Education
Appalachian/Rural Health Perspective
Mary Babb Randolph Cancer Center
Director of Education, Information, and Prevention
West Virginia University
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Sandral Hullett, M.D., M.P.H.

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Family Healthcare of America
Eutaw, AL

Linda Burhansstipanov, Dr.P.H., M.S.P.H.

Director, Native American Cancer Initiatives
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Lovell Jones, Ph.D.

Professor and Director
Experimental Gynecology-Endocrinology
MD Anderson Cancer Center
Houston, TX

Beverly Campbell

The Scientific Consulting Group, Inc.
Gaithersburg, MD

Margorie Kagawa-Singer, Ph.D., M.N., R.N.

Assistant Professor
Community Health Sciences
Asian American Studies
UCLA School of Public Health
Los Angeles, CA

Patricia Golden, M.P.H.

Liaison for Minority Health Data
National Center for Health Statistics
Hyattsville, MD

LaMar McGinnis, M.D.

Medical Consultant, American Cancer Society
Professor, Emory University
School of Medicine
Atlanta, GA

Jeff Henderson, M.D.

President and CEO
Black Hills Center for American Indians
Rapid City, SD

Barry Miller, M.S.P.H.

Epidemiologist
Division of Cancer Control and Population
Sciences
National Cancer Institute
Rockville, MD

Robert Hiatt, M.D., Ph.D.

Deputy Director, Division of Cancer Control and
Population Sciences
National Cancer Institute
Rockville, MD

Data Working Group Meeting Participants (Continued)

Jeanette Noltenius, Ph.D.

Latino Council on Alcohol and Tobacco
Washington, DC

Amelie Ramirez, Dr.P.H.

Leadership Initiative on Cancer
Associate Director, Chronic Disease Prevention
and Control Research Center
Associate Professor, Baylor College of Medicine
San Antonio, TX

Elena Rios, M.D., M.S.P.H.

President, National Hispanic Medical Association
Director, Hispanic Serving Health Professions
Schools
Washington, DC

Susan Shinagawa

Cancer Survivor
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JoAnn Tsark, M.P.H.

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Armin Weinberg, Ph.D.

Director, Chronic Disease Prevention and Control
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Hannah Weir, Ph.D.

National Center for Chronic Disease Prevention
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Laura Williams, M.D.

Irvine, CA

Evaon Wong Kim, L.C.S.W., M.P.H., Ph.D.

Oncology Social Worker
Department of Social Services
San Francisco General Hospital
San Francisco, CA

Appendix B:

Agenda for the September 25-26, 1999 Data Working Group Meeting

DATA WORKING GROUP MEETING
September 25-26, 1999
Grand Hyatt Hotel — 1000 H Street, NW
Washington, DC

Purpose of Meeting: To define the data collection and analysis issues of concern to ethnic minority and medically underserved populations concerning cancer incidence and survival.

Meeting Co-Chairs — Jim Hampton and Gil Friedell

AGENDA

Saturday Morning

Convene

9:00 AM

Statement of the Problem — IOM Report as Background (30)	Gil Friedell, Amelie Ramirez
Cancer Control Research Perspective (15)	Bob Hiatt
Issues for American Indian and Alaska Native Populations (20)	Jim Hampton, Jeff Henderson
Issues for Hispanic Populations (20)	Amelie Ramirez, Jeannette Noltenius
Issues for African American Populations (20)	Sandra Hullett, Lovell Jones
Issues for Asian American and Pacific Islander Populations (20)	Evaon Wong-Kim, Reggie Ho, Susan Shinagawa, JoAnn Tsark
Issues for Rural, Poor White, Medically Underserved (Appalachian) Populations (20)	Pam Brown, Gil Friedell

General Discussion

Saturday Afternoon (Working Luncheon)

Socioeconomic Status

Gil Friedell, Gopal Singh

Cultural Differences

Jim Hampton

Data Collection Needs and Challenges
Barry Miller

LaMar McGinnis, Hannah Weir,

Data Needed to Mount Effective Cancer Control Activities for and by Ethnic Minorities and the Medically Underserved (i.e., cancer prevention, screening, detection, diagnosis, treatment, rehabilitation, quality of life)

Armin Weinberg

General Discussion

Adjourn for the Day

5:00 PM

Sunday Morning

Reconvene (Breakfast Buffet Available at 7:30 AM)

8:30 AM

Summary of Meeting and Agreement on Statement of Issues from the Standpoint of "Consumers/Users" for Discussion in November Meeting

General Discussion

Adjourn Meeting

11:00 AM